

University of Otago



Perspectives on gaps in communication with  
breast cancer patients in New Zealand

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## Abstract

The world of breast cancer is pink, female-centric and aimed at an older, post-menopausal demographic. Whilst it is fitting that health campaigns be aimed at the majority of patients registering with the disease, these characteristics are not appropriate for everyone diagnosed with breast cancer. Ministry of Health statistics show that each year in New Zealand, around 25 men and 300 women under the age of 45 are diagnosed with breast cancer. This number is growing, with the number of breast cancer diagnoses increasing by approximately 18% in New Zealand over the last decade. Yet men, young women and other atypical patients are largely unrepresented in current communication resources, tools and national health promotion campaigns.

This thesis explores perspectives of health professionals, develops resources and makes recommendations to improve communication with patients during their breast cancer journey. In order to address a gap in current breast cancer communication, the focus was on the 'atypical' patient experience. For the purposes of this research, 'atypical' includes pre-menopausal women, Māori and Pasifika, men, people who have not had families and 'high-risk' or 'vulnerable' members of society. Through in-depth exploration of health professionals' perspectives about communication with atypical patients in New Zealand during their breast cancer treatment, this research documents some of the current barriers to effective communication and knowledge exchange.

Semi-structured interviews were conducted face-to-face with eleven health professionals and support service providers. The interviews were transcribed and inductive qualitative thematic content analysis was conducted. Age, Gender, Culture, High-Risk and Survivorship were categories discussed by participants in relation to improving communication for a wider spectrum of breast cancer patients. The most common factor discussed by interviewees was Age. Younger women are likely to face specific emotional and psychosocial problems, which may require additional management and multi-disciplinary support. Participants also frequently mentioned Gender. Men can be uncomfortable presenting with symptoms of a change in their

breast or chest area to a doctor, causing a delay in diagnosis. Any delays in the diagnostic process can have negative results on the general prognosis of the disease so early detection is important in order to improve breast cancer survival rates. Another area which needs improvement in communication involves specific cultural needs. There are lower percentages of Māori and Pacifica women attending breast screening as compared to other groups, which results in a reduced rate of early detections, worse outcomes and higher mortality rates for these patients. 'High-risk' or vulnerable patients include sex workers, people with drug addictions and/or mental health issues. These patients are generally unrepresented in current campaigns. They are less likely to seek medical care for symptoms, have poorer experiences in relation to knowledge exchange with health professionals and are less likely to attend for regular treatment and medication in follow up medical care.

Issues surrounding Survivorship were also commonly mentioned in research interviews, in that not enough is being done at the tail end of treatment to assist breast cancer survivors in processing their experience. This hinders reintegration back into society. With approximately 87% of patients in New Zealand now surviving breast cancer, participants pointed out that not enough is being done to prepare patients for the end of the treatment pathway. Interviewees described many survivors of breast cancer undergoing a 'crash' physically, mentally, socially and financially, in the three to twelve months after treatment. This crash has been shown to have negative psychosocial outcomes affecting not only the patient, but also their caregivers, families and thus society as a whole.

Recommendations from this study include: development of age appropriate literature and tools for young adults with cancer, development of specific strategies for reaching high-risk patients, ensuring gender inclusivity in campaigns and online information, even for a 'female-centric' disease like breast cancer and improvement of cultural awareness and methods to avoid cultural and linguistic barriers.



Medical professionals and support service personnel should be provided with resources to enable improved communication. Three short videos were produced to increase awareness about some of the issues faced by atypical patients. To mitigate negative survivorship issues, patients should be supported in exerting greater control of their experience. Benefits of a gym programme, EXPINKT™ are explored in a documentary, “I’m Still Here”. Conducted as a paper within the School of Education at the University of Otago, the ‘EXPINKT™’ programme provides supervised and personalised exercise training for current and post-treatment breast cancer patients.



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Tragedy transcended can be joyous.

This thesis is the best possible outcome for breast cancer blindsiding me at the age of 32. At that difficult time, I felt the loneliness of always being the youngest person in the hospital waiting room, or the chemo ward, or the radiation clinic. The emotional disconnect of reading pamphlets, watching cancer DVD's and utilising tools and resources that I didn't identify with, that didn't apply to me. The catharsis of now facing that beast, of besting it with words rather than swords, gives me a great sense of accomplishment. My transcendence feels complete.

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## Forward

My diagnosis of breast cancer in 2009, at the age of 32 ignited my passion for this project. With no family history of breast cancer or personal experience with this disease to draw from, I felt ill-equipped to cope with the unknown outcomes of my prognosis and treatment. The first thing I did after my GP confirmed the diagnosis of Stage 2 aggressive hormone receptive ductal carcinoma was to go online for information. Rather than feeling informed I felt overwhelmed with imagery of mature, silver-haired ladies banding together in nurturing support. The breast cancer resources assured me that I was not alone. That this was largely a survivable cancer if detected early (which mine was) and that there were resources, support groups, online forums and people in the community to support me during my cancer pathway. But as I logged off, I felt trepidation and the heaviness of separation. None of the images I had seen depicted a person like me, in her early 30's, who did not have a spouse to rely on and who had never had children.

I attended the Peter MacCallum Cancer Hospital in Melbourne, Australia to commence a year's worth of appointments, meetings, blood tests, surgeries, weigh-ins, poking, prodding, bleeding, chemotherapy cocktails, vomiting and radiation treatment. The hectic and rigorous schedule of my life providing some distraction, but my sense of loneliness was exacerbated. I was always the youngest person sitting amongst rows upon rows of waiting patients. Self-consciously, I would reach for a magazine, although the knitting patterns and baking recipes would provide me with little solace. I asked the Breast Nurse Coordinator if it was rare for a young woman like me to present with breast cancer and she nodded affirmatively. "We shall nickname you anomaly!" she said with a smile. "But don't worry... this is a good thing. I've never seen so many consultants attend the first round-table discussion on a patient. You're getting very special attention."

On some level, I found this comforting and I did receive incredible medical support that year. But I was not prepared for the devastating emotional crash that I experienced, a

year later, when the reality of my new 'norm' truly hit. When my disfigurement, crippling fatigue and failure to reconnect with myself existentially became overwhelming sensations in my day-to-day life. When people stopped calling me "brave" and a "survivor", I became just a normal person again, although I didn't feel normal at all. Nor was I comfortable with the moniker of being brave for just surviving a disease, for going through the motions. I did not feel courageous or heroic. I felt unlucky, vulnerable and flawed.

I focused on my desire to get on with life and not malingering. I returned to work, to socialising, to dating, none of which I felt present in, nor particularly motivated to return to. In the dark hours of night, I would lay awake pondering the rude revelation that the world had not stopped for me. People had gone about their days, and their lives, and I felt acutely aware that I was infinitesimal. I questioned this new hyperawareness and where it had come from. Had I separated somehow from myself at the point of diagnosis and splintered? Skewed off course? Had I not asked for enough help? Were these feelings normal? There was little support for me emotionally at home. My mother's progressive Alzheimer's provided me with no relief and this, along with geographical remoteness, contributed to the tremendous sensation that I was alone, and somehow broken.

This was my crash.

It took several months of post-traumatic stress type counselling for me to reconnect with myself after my cancer battle. Through this psychological support, I started to be able to process everything I had been through. I started to learn to accept my body as something to cherish rather than be repulsed by. I accepted my mismatched and scarred breasts as "battle scars". I celebrated my inner strength, tested in ways I had never imagined and I reiterated Reinhold Niebuhr's 'Serenity Prayer' daily. I hoped the universe would somehow grant me the serenity, courage and wisdom to have a fulfilled life without regrets. And I applied that mantra consistently, achieving more in the next few years than I had in the ten years before my diagnosis.

Which leads to me here, now, after seven years in remission. Celebrating the life of a daughter, whom I didn't think I could have and a partner who loves me just as I am. I am now aware of the legacy I want to leave for them, my own mantra that life is a gift. That is why I am here now, doing this thesis.

Given my personal involvement and passion for this topic, mechanisms were carefully put into place to ensure data collection and analysis were robust and reliable. This is discussed in the methodology section of this thesis. This project was an opportunity for me to explore, from an academic perspective how we communicate to breast cancer patients in New Zealand. It allowed me to take a proactive approach to strive to improve cancer communication, so that atypical patients do not sit in a waiting room feeling so alone, feeling like an 'anomaly'.





## **CHAPTER ONE: LITERATURE REVIEW**

### **1.1 Introduction**

This thesis tackles some of the challenges surrounding effective and supportive communication and knowledge exchange with breast cancer patients in New Zealand and describes both original research and creative components. The focus of the research component is to explore health professionals' and care-givers' perceptions about communication with breast cancer patients via in-depth interviews. The overarching research question being: 'What are perspectives of health care practitioners about gaps in communication with breast cancer patients in New Zealand?'

My original interest was anomalous patients, and so there is a focus on them. My creative component includes three short videos (webisodes) about the anomalous experience, created to be viewed online by patients, care-givers and health-care providers. My research identified survivorship as a particular area that requires more attention and better communication, so the creative component was expanded to also include a 26-minute documentary about EXPINKT™, a gym in Dunedin, New Zealand which provides supervised exercise for breast cancer survivors. It is hoped that the research results and the resources created will improve both communication and outcomes for all breast cancer patients.

### **1.2 Thesis Structure**

Chapter One of this thesis contains a review of current and relevant literature regarding breast cancer, breast cancer culture, communication needs, the treatment pathway, descriptions of the 'atypical' breast cancer patient and the research aims and objectives. This chapter provides the foundation and rationale for the research project as well as creation of the digital media resources (the "Creative Component"). My aim is to improve recognition of the special needs of the 'atypical' experience with breast cancer

in New Zealand, and to provide resources for use in the breast cancer and oncology field.

Chapter Two provides an overview of the research project conducted with health-professionals who work with breast cancer patients in New Zealand. The study determines perceptions about barriers affecting breast cancer communication and identifies groups that are likely to have an 'atypical' patient experience. This chapter describes the research design, including ethics approval, recruitment, methods for data collection and analysis.

Chapter Three includes the research results and discussion of the findings. The focus of this chapter is the gaps of and barriers to effective communication and knowledge exchange, as well as the identification of categories that help to identify potential atypical individuals. These include Age, Culture, Gender and High-Risk patients. The issues surrounding Survivorship, which affect not only patients during treatment and cancer survivors (post-treatment) but also society as a whole, are discussed along with recommendations for ways to mitigate negative survivorship issues post-treatment, for metastatic or terminally ill breast cancer patients as well as those in remission.

Chapter Four describes the thesis creative components, which comprise the major effort of this project. The themes and areas highlighted in the research component were explored creatively, through the design and implementation of digital media resources - namely three 3-minute webisodes and one 26-minute documentary film. This chapter describes the creation of tools that can be shared online and viewed by both the public and health professionals. The webisodes and the documentary, were designed to raise awareness of issues encountered by atypical patients, the barriers they face relating to effective communication and knowledge exchange in the breast cancer realm, and to provide an exemplar of a research-based exercise program that may mitigate many of the negative physical and psychosocial impacts for breast cancer survivors.

Chapter Five explores the promising outcomes for the cross-analysis findings on the barriers to effective communication for atypical breast cancer patients in New Zealand. It summarizes the value of the digital media resources contained within this thesis in conjunction with the research findings. This chapter concludes with recognition of limitations, recommendations for future study to be undertaken in this field, and suggestions on further development of inclusive communication resources aimed specifically at those who fit outside the normal demographic of breast cancer patients, the ‘anomalies’.

### **1.3 Health Communication: The Global Issue**

Health-related communication and promotion is the process of educating and empowering the public to take control of and ultimately improve their health (WHO, 2014). The “Ottawa Charter for Health Promotion” (17-21 November 1986), describes effective health promotion as allowing people to feel empowered. With empowerment, one can strive to attain holistic physical, mental and social well-being, which in turn improves our ability to cope with our environment. Thus, health is not just the objective for living, but rather a resource for improvement in our everyday lives (WHO, 1986). In view of this, the effective promotion of health becomes the responsibility of society as a whole, rather than just an issue for those in the health sector.

The way which we process the information we receive can often be determined by different interrelated factors such as age, gender, culture, income and educational levels attained (Jung, et al. 2013) as well as beliefs, values, awareness, skills and understanding (Longnecker, 2016). Effective communication of health-related matters must include a rigorous process of both scientific development and careful dissemination (Heesoo, et al. 2016). This is particularly relevant during specific health-related campaigns, such as those associated with breast cancer. We, as individuals, do not passively consume information; communication is more effective if we actively participate in obtaining the information in a form of knowledge exchange (Bernhardt, 2004).

The effective dissemination of health-related information can have positive effects on behaviour, as well as on views and perception of health-related matters (Niederdeppe, et al. 2008). The use of digital media can be effective in getting health messages across to a global audience. However, easily accessed digital communication and information provided through the media related to cancer, can also result in negative effects on behaviour. This can be exacerbated by a fear of the disease, or lack of experience with it. Therefore, the way in which cancer related information is communicated is important (Heesoo, et al. 2016).

To encourage and facilitate discussion of issues surrounding health and its communication, the World Health Organisation (WHO, 1986) outlined a range of social and environmental interventions which are integral to the improvement of health. These include:

- Building healthy public policy - with greater equity being fostered with effectively coordinated action regarding health, income and social policies;
- Creating supportive environments - to encourage reciprocal maintenance, to take care of each other, our communities and our natural environment on a global scale;
- Strengthening community actions - to encourage the empowerment of communities, their ownership and control of their own endeavours and destinies;
- Developing personal skills – by utilising school, work, home and community settings to prepare individuals for life's various stages, including coping with chronic illness and injuries; and
- Reorienting health services – by embracing a global mandate of respecting cultural needs and encouraging more effective methods of knowledge exchange between the health sector and broader social, political, economic and physical environmental components.

Good communication is key to these interventions and is the focus of this thesis.

## **1.4 Breast Cancer**

Breast cancer is one of the highest cancer killers in the world of women over 30 years of age and (World Cancer Research Fund International, 2017). In order to understand the importance of breast cancer awareness campaigns and national health promotion strategies, an outline is provided of what breast cancer is, as a disease.

Breast cancer develops as a lump in the tissue of the breast and can manifest as a change in the shape of the breast, present as dimpling or red patches on the skin and/or as discharge from the nipple (National Cancer Institute, 2014). In 2012, there were 1.68 million cases of breast cancer and 522,000 deaths globally (World Cancer Report, 2014). The disease can manifest at any age but predominately presents in women aged between 50 to 70 years old (The Cancer Society, 2012).

Whilst the causes of breast cancer are uncertain, contributory risk factors include: age; previous breast cancer; atypical hyperplasia (increased number of abnormal cells) identified in a breast biopsy; family history of breast cancers; presence of a faulty BRCA gene (the normally functioning BRCA1 gene assists with the repair of DNA); having an altered gene that is associated with the risk of breast cancer; hormone replacement therapy; alcohol consumption; and obesity. The prognosis for a patient depends on the type of cancer, the extent to which it has spread and the patient's age (National Cancer Institute, 2014).

## **1.5 Breast Cancer in New Zealand**

Approximately seven New Zealand women will be told they have breast cancer every day (Ministry of Health NZ, 2015). Life expectancy is five years or longer if the cancer is detected early enough but tragically, more than 600 New Zealand women die from the disease annually (Ministry of Health NZ, 2015). To ensure effective public awareness of this disease, the Ministry of Health in New Zealand has actively supported campaigns by the Breast Cancer Aotearoa Coalition, the Breast Cancer Foundation, The Cancer Society

and Breast Screen Aotearoa, with links provided on the Ministry's website (Ministry of Health, 2015). These campaigns have been successfully raising awareness of the disease symptoms, highlighting the benefits of early detection and educating communities about the government resourced National Screening Unit program in New Zealand (National Screening Unit, 2015).

## **1.6 Ministry of Health NZ: Breast Cancer Statistics**

A report published by the Ministry of Health, Cancer: New registrations and deaths (2011) provides the most current available breast cancer statistics for New Zealand. According to the report, in 2011 more than 2,800 women were diagnosed with breast cancer (with provisional data at that time showing this number increased to more than 3,000 in 2013); 332 women were under 45 years old; 27 men were diagnosed.

Māori women registered with a breast cancer rate 1.4 times higher than non-Māori and the mortality rate was 1.6 times higher than the rate for non-Māori. One reason for the increased mortality rate for Māori is that they tend to present with breast cancer at a later stage of the disease. The reasons for their presenting late are complex but are generally attributed to the low rate of attendance for screening mammograms by Māori women. Māori women have the highest incidence of breast cancer of any indigenous population in the world (Jemal et al., 2010; Condon et al., 2003) and have a 28% higher age-standardised incidence of breast cancer compared to non-Māori in New Zealand (117.2 compared to 90.6 per 100 000 population for 2006–2009). Pacifica women are 54% more likely to die of breast cancer than other New Zealand women, despite having similar risks of developing the disease.

These statistics highlight significant numbers of atypical patients with breast cancer in New Zealand. Atypical patients considered in this thesis are those who fit into the categories discussed in the following sections.

## **1.7 Atypical Breast Cancer Patients**

### **1.7.1 Young Adults**

Breast cancers are less common in women under the age of 50. Approximately 70% of women diagnosed with and about 80% of those who die from breast cancer are aged 50 years or older (Breast Cancer Aotearoa Coalition, 2016). Although the peak incidence of breast cancer is between the ages of 50 to 70, approximately 8% of all breast cancers are diagnosed before the age of 40 (Breast Cancer Register, 2011). The principles of the management of breast cancer in young women are the same as in older women. However, treatment choices can vary greatly from those offered to breast cancer patients who have already undergone menopause.

Some issues and information needs of young adults with breast cancer include fertility preservation, impact on sexuality and body image, early menopause and bone health, treatment during pregnancy, financial implications and discussion of cancer with children (New Zealand Breast Cancer Foundation, 2013). As a result of these issues and additional treatment choices, younger women can be more likely to face emotional and psychosocial problems, which may require additional management and multidisciplinary support (Narod, 2012). Young breast cancer patients can also have more aggressive tumours due to their age. Therefore, treatments such as chemotherapy, endocrine therapy and radiotherapy are commonly offered based on the histology and in discussion with the multidisciplinary team (Breast Cancer Aotearoa Coalition, 2016).

### **1.7.2 Males**

Whilst breast cancer is considered a predominately female disease, it can also affect males, with approximately 25-30 New Zealand men being diagnosed each year (Ministry of Health, 2010). The breast cancer disease in males is the same that affects females, so the diagnosis and treatment for both genders are similar. The prognosis for men with breast cancer is similar to that for women at the same age and stage of the cancer, with the 5-year survival rate in New Zealand being 86% (Ministry of Health: Wellington (unpublished data) and OECD, 2007). Some men may be uncomfortable

presenting with symptoms of a change in their breast or chest area to a doctor; this can result in a delay in diagnosis. Any delays in the diagnostic process can have negative results on the general prognosis of the disease, so early detection in men contributes to higher breast cancer survival rates (New Zealand Breast Cancer Foundation, 2013).

### **1.7.3 Māori and Pacifica**

As discussed previously, breast cancer statistics for Māori and Pacifica women in New Zealand are alarming. Māori women are 21% more likely to be diagnosed with breast cancers and 30% less likely to be diagnosed early (Robson et al., 2010). They are also 72% more likely to die from breast cancer than non-Māori (Blakley et al., 2007). Other data suggest Māori women are also predisposed to getting breast cancer at a younger age (McCredie et al., 1999). Contributing to these concerning statistics is the fact that lower percentages of Māori and Pacifica women are attending breast screening as compared to other ethnic groups, which results in a reduced rate of early detections (Breast Cancer Aotearoa Coalition, 2016).

### **1.7.4 High-Risk or ‘Communication Vulnerable’ Patients**

A study conducted by Maly et al (2015) found that the quality of life amongst low-income women with breast cancer would be significantly improved by communication methodologies focused on the empowerment of patients in knowledge exchange with health providers. It has been largely documented that there is a disproportionate division of breast cancer burden amongst certain socioeconomic groups (Nelson, et al., 2002). Patients diagnosed with breast cancer that have lower levels of income and education can experience a reduction in their quality of life, largely due to the decreased effectiveness in health professional-patient communication (Siminoff, et al., 2006). Therefore, it is important to continue to develop targeted communication for high-risk, or communication vulnerable, patients moving forward.



## **1.8 Communication to Atypical Patients**

New Zealand public health awareness websites, Ministry of Health brochures and literature and multimedia resources provide extensive information pertaining to the National Breast Screening program and other diagnostic and support initiatives. However, the communication is usually aimed at the female-centric, post-menopausal or 'typical' breast cancer patient demographic. Whilst accurate targeting is integral to the success of health promotion awareness campaigns, the characteristics of those targeted do not effectively encompass all breast cancer patients in New Zealand. Despite Ministry of Health statistics reflecting the diversity of patient demographics (Ministry of Health, 2014), atypical patients (such as young adults, males and non-Europeans), are largely underrepresented in current communication resources, tools and national health promotion campaigns. This kind of stereotyped campaigning also fosters the ideology of a breast cancer culture.

## **1.9 Breast Cancer Culture**

Breast cancer communication is pink, gender specific and designed for a post-menopausal demographic. Online campaigns, brochures and information disseminated in New Zealand widely utilise mature women as the 'face' for breast cancer campaigns (Figure 1.1). Whilst it is essential that health campaigns be aimed at the majority of patients registering with a particular disease, these characters do not necessarily effectively represent the wider spectrum of people diagnosed with breast cancer in New Zealand.



Figure 1.1 Being Breast Aware Campaign (<http://nzbcf.org.nz/e-guide.aspx>) New Zealand Breast Cancer Foundation website. Retrieved December 2016.

According to Barbara Ehrenreich's 2001 article in Harper's Magazine, "Welcome to Cancerland", the breast cancer 'pink ribbon' culture is one defined by the activities, attitudes, and values that shape public perception of breast cancer in the public domain. The dominant values most often attributed to the breast cancer culture are ones of selflessness, joyfulness, unity, and hope. There is also the common conception that breast cancer patients who have suffered bravely, have earned their place in the culture. But Ehrenreich believes this is a constructed misconception:

*The woman with breast cancer is given a cultural template that constrains her emotional and social responses into a socially acceptable discourse. Potentially hardened by the emotional trauma of a breast cancer diagnosis and the suffering of extended treatment, the woman with breast cancer is deemed to transform herself into a stronger, happier and more sensitive person, grateful for the opportunity to become a better person. Breast cancer therapy becomes a rite of passage rather than a disease. (Ehrenreich, 2001, p.43).*

Ehrenreich's stance supports opinion that there can be negative associations with the ideological culture surrounding breast cancer, despite it helping maintain the disease's

domination as the foremost women's health issue. This in turn fosters the notion that society is being proactive about the disease thus supporting the social, political, and financial power of breast cancer activists (Sulik, 2010). However, whilst raising awareness of breast cancer is an important pursuit, this type of 'empowered' culture associated with the health campaigns and societal pre-conceived notions of breast cancer can potentially exclude those who do not associate their own cancer journeys with feelings of joyfulness, unity, and hope. A feeling of exclusion amongst breast cancer patients and survivors can become an undesired by-product of the existing breast cancer culture. Therefore, it is important to increase a sense of inclusivity when developing communication in relation to breast cancer.

An inclusive approach to communication is desirable. With research showing appropriate information provision leading to improved health competence, a better sense of control and superior symptom management by patients (Arora, 2002). There is a considerable amount of decision-making to be made by a newly diagnosed cancer patient during their treatment pathway. Therefore, providing inclusive, supportive and positive communication to assist with effective treatment preparation may lead to an increased ability to cope with the disease and improve recovery once treatment is completed (van der Meulen et al., 2008).

### **1.10 Treatment**

The breast cancer management pathway can require both surgical and sustained medical treatment for patients, which can take place over several weeks or months (New Zealand Breast Cancer Foundation, 2013). The treatment may be local (i.e. removing or destroying the cancer within the breast and surrounding areas) or systemic (i.e. treating the whole body). The different treatments for breast cancer include surgery, radiation treatment, chemotherapy and hormone treatment. The treatment options depend upon the type, grade (how abnormal the cells look), size, and stage of cancer (whether it has spread or not), the patient's age, general health and personal choices (New Zealand Breast Cancer Foundation, 2013). It is important to

clarify the modes of treatment so as to show the length and breadth of the treatment pathways patients endure in order to save or prolong their lives.

### **1.10.1 Surgery**

The aim of breast cancer surgery is to remove cancerous tissue thus reducing the risk of recurrence, whilst maximising the cosmetic result and the patient's quality of life. Surgically removed tissue is sent for pathological analysis to inform further treatment recommendations (New Zealand Breast Cancer Foundation, 2013).

### **1.10.2 Radiation Treatment**

Radiation treatment is the use of high-energy radiation to destroy cancer cells or prevent them from reproducing. This is often administered to patients daily over several weeks. Side effects of radiation treatment can include fatigue and reddening or 'sun burning' of the skin (New Zealand Breast Cancer Foundation, 2013).

### **1.10.3 Chemotherapy**

Chemotherapy is the treatment of cancer using cytotoxic (anti-cancer) drugs which stop cancer cells from dividing and multiplying. Treatment is given at one to three weekly intervals and can last for several months. Side effects can include risks of infection, hair loss, nausea/fatigue, irregular menstruation or cessation of regular menstruation (New Zealand Breast Cancer Foundation, 2013).

### **1.10.4 Hormone Treatment**

Links have been found between the female hormones, oestrogen and progesterone, and the onset of breast cancer. Patients who register with a hormone receptive tumour may be offered a hormone treatment, often for several years once treatment has finished. Pre-menopausal patients also may have menopause induced in order to cease the production of hormones in their bodies (The Cancer Society, 2012).

## 1.11 Research Aims and Objectives

The cancer treatment pathway can be long and arduous. It can be filled with trepidation, anxiety and a host of serious and long-lasting effects not only on the patient, but also on their families and caregivers. Cancer patients must make a series of serious decisions about treatment options during diagnosis and treatment whilst simultaneously reviewing their own personal set of circumstances including their physical, psychological, social and financial well-being. Research shows good communication is an effective tool in assisting patients not only during their cancer treatment but also well into their post-treatment reintegration back into society. Breast cancer patients who had good communicative experiences described feeling less vulnerable, experiencing positive patient-clinician alliances and feeling control and mastery over the cancer experience (McWilliam et al., 1999).

This thesis explores health professionals' perspectives about current communication practices with atypical breast cancer patients in New Zealand. This is achieved through in-depth interviews of those at the 'front line' of the dissemination of breast cancer communication. The desired outcome ultimately is improved provision of information to 'atypical' patients during their breast cancer pathway. For the purposes of this study, the definition of 'atypical' is those who fall outside of the demographics targeted by current breast cancer campaigns (i.e. young adults, pre-menopausal women, men, Māori/Pacifika, those who have not yet had families, 'vulnerable' members of society etc.).

Heesoo et al, (2016) report that despite the considerable increase of cancer survival, there are limited studies of the lack of health information, the barriers to effective communication, and the complications surrounding survivorship issues, post-treatment. This is the very gap this thesis aims to focus on using an interpretivist paradigm, which allows for meaning to emerge throughout data collection and analysis (Dudovskiy, 2017).

For interpretive researchers, “reality” (real or perceived) is a social construct (Mayers, 2008). This paradigm rejects the objectivist view that consciousness resides independently of meaning within the world view (Collins, 2010). Thus, using an interpretivist approach, allows a researcher to appreciate people’s differences (Sanders, 2012), which is paramount when exploring personal experiences. This research method allows exploration of the personal experiences of participants in this project. This in turn, provides a spotlight on the gaps or barriers to effective communication as experienced by those in it. This provides data on which further studies can be built, in order to diminish exclusivist, or poor communication outcomes in the future.

Evidence shows that an inclusive approach to communication can have a positive effect on both the patient and the overall breast cancer treatment pathway. This includes the nature and quality of effective patient-clinician knowledge exchange, the outcomes related to decision making and the psychosocial experiences of patients (Thorne et al., 2005). These outcomes can significantly improve a patient’s ability to successfully re-enter society upon the completion of their cancer treatment.

The additional intention of this research is to assist in the national initiative for breast cancer patients in New Zealand to exert mastery and control over their cancer experiences (McWilliam et al., 1999). This can be achieved by addressing gaps in our current communication and knowledge exchange materials disseminated during the breast cancer pathway and highlighting areas that could be improved based upon industry professionals’ recommendations.

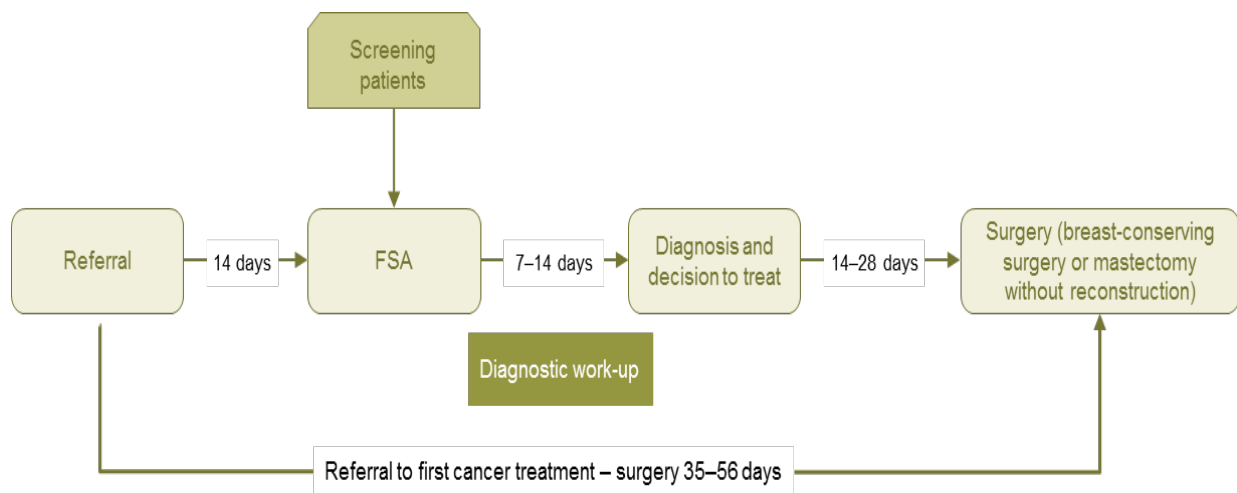
The objectives of this research are to explore perspectives of health and support service professionals about their current communication with breast cancer patients in New Zealand, and to determine gaps in current methods. Through interpretivist methods of research analysis, this thesis aims to establish industry relevant recommendations for improvement based on the professional opinions of the participants in this study and to use the results to create appropriate communication resources.

It is hoped that the data collected within this case study, the creative components and the conclusions and recommendations made in Chapter 5 will encourage more effective knowledge exchange to occur during and after the treatment experience with positive outcomes for both patients and providers. Directions for further research are suggested to improve communication with all breast cancer patients in New Zealand.

### **1.12 New Zealand Breast Cancer: Standards of Care**

In 2013, the National Breast Cancer Tumour Standards Working Group created a new 'Standards of Care' to foster best practices management of the breast cancer pathway in New Zealand (Ministry of Health, 2014). These standards were developed as a part of the Faster Cancer Treatment programme's approach to providing both quality and efficient care for cancer patients. The Faster Cancer Treatment model is a recently implemented Ministry of Health programme that aims to improve patient experiences by the standardisation of pathways and timeframes throughout New Zealand. The standards aim to promote coordinated and consistent standards of service nationally, with a focus on equity.

A timeline of approximately 56 days from referral to surgery is the breast cancer 'pathway' standard for patients in New Zealand (Figure 1.2). According to the Ministry of Health (2013) the FSA or "First Specialist Assessment" describes the patient's first face to face appointment with a registered medical practitioner or nurse practitioner for the purpose of the initial assessment of their condition.



*Figure 1.2 The Breast Cancer Pathway, from referral to first cancer treatment. Retrieved from: “National Breast Cancer Tumour Standards Working Group” (2013). Standards of service provision for breast cancer patients in New Zealand—provisional. Wellington: Ministry of Health.*

Figure 1.2 demonstrates the aim for New Zealand breast cancer patients who are on the standard pathway to meet the Faster Cancer Treatment indicator timeframe of 56 days from referral to surgery. Breast cancer service standards were established by the National Breast Tumour Standards Working Group who were tasked with addressing the points of key interest across the breast cancer pathway of care. With these standards intended to be equally beneficial to all patient demographics, the Ministry of Health recommended each regional District Health Board adapt to meet the specific needs of those populations who tend to suffer relatively poor health outcomes, such as Māori and Pacifica (Ministry of Health, 2014).

The focus of these established standards of care are: prevention and early identification (via screening and genetic services); timely access to services; referral and communication; investigation; diagnosis and staging; multidisciplinary care; supportive care; care coordination; treatment; follow up and surveillance; special topics (e.g. pregnancy and breast cancer in younger women); and clinical performance monitoring and research.



Whilst breast cancer mortality in New Zealand has fallen by 19.6%, diagnoses have increased by 18% in the last decade (Ministry of Health, 2014). Breast cancer is becoming the leading cause of cancer related deaths in New Zealand, resulting in the deaths of more than 650 patients per year. Therefore, the Ministry of Health and government initiatives such as the Healthier Lives National Science Challenge are actively looking to address issues that can adversely affect the best-practice outcomes for patients. Improving breast cancer communication and knowledge exchange between patients, caregivers and health professionals is one of these challenges.

### **1.13 The Cancer Trajectory**

A cancer diagnosis brings about a multitude of stressors for patients and their caregivers. As treatment commences, these stressors are often exacerbated by the rigorous demands of the cancer treatment pathway, which can include physically challenging and even life-threatening treatments. Potential outcomes include physical disabilities and scarring, severe and sometimes debilitating fatigue, and residual pain when the cancer is in remission or 'cured' (Hewitt et al., 2005). These consequences can be further exaggerated in the presence of additional psychological and social stressors, such as absent familial or social supports and reductions in financial income due to illness. Physical, psychological, and social stressors are all frequently interlaced, both resulting from and contributing to one another (National Academies Press, 2008).

Clear aims must be established to address what the communication needs of patients actually are (Hack, et al., 2005), at what stage the patient wants to receive the information (Hack et al., 2005; Leydon et al., 2000), how the care provider can convey the information in a supportive way (Hack et al., 2005; Leydon et al., 2000), how to facilitate effective knowledge exchange whilst encouraging patient decision-making and ensuring best outcome practices are maintained (Thorne et al., 2005). Communication needs of patients are varied and become especially relevant when considering the end of life care aspect of the cancer trajectory (Figure 1.3).

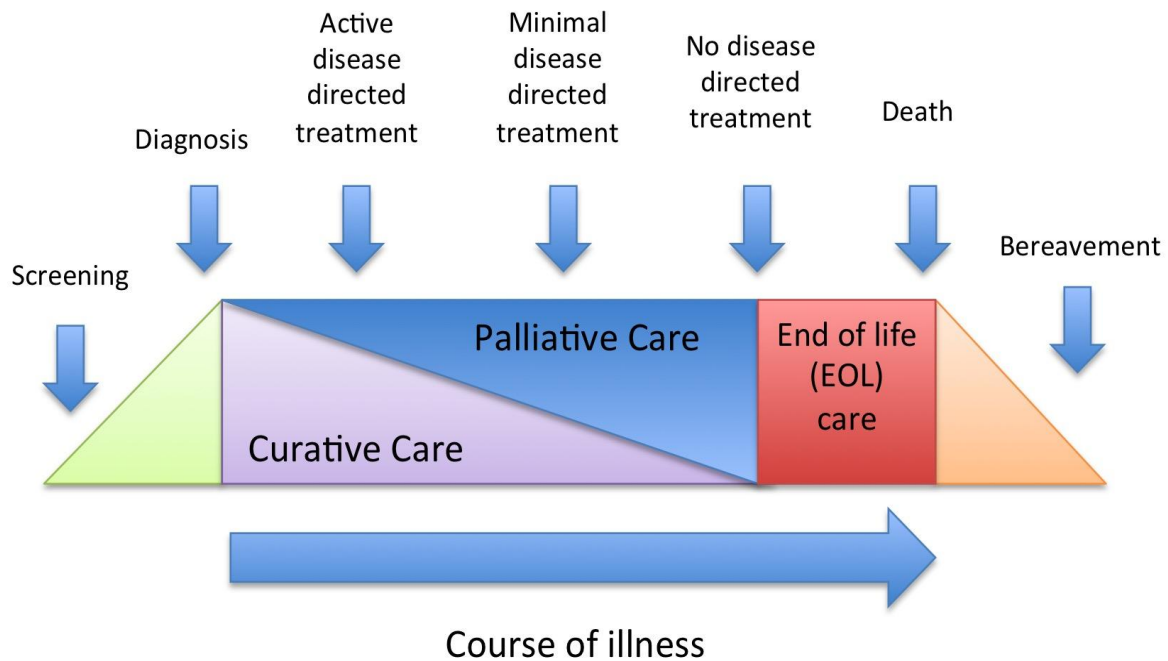


Figure 1.3 The continuum of palliative care and end of life care. Retrieved from: <http://depts.washington.edu/pallcare/training/ppt.shtml>

### 1.14 Breast Cancer Communication: Methods & Requirements

The considerable advancements in the biomedical care for cancer have not been equally matched in the care for the lasting psychological and social effects that linger long after medical treatment has ended (National Academies Press, 2008). In fact, too often cancer survivors and their caregivers report that their cancer care providers did not meet their needs psychosocially, that symptoms of stress or depression were not recognised and that lack of psychosocial support went unnoticed (National Academies Press, 2008). The primary goal of an ideal medical management of cancer communication upon diagnosis and during treatment comprises of two key areas, each with its own expectations and associated secondary needs: discussions regarding the status of the disease, its diagnosis and prognosis; and discussions about treatment and management.

Patients' communication needs can differ. A study conducted in the United Kingdom showed that 89% of patients wished to be informed of their diagnosis, and 87% of

patients wanted to receive all possible information, showing that not all patients require or seek out full detailed information pertaining to their illness (Jenkins et al., 2001). Therefore, health providers and support services professionals may find it inappropriate to provide a one-size fits all approach, when the individual needs and requirements for communication can vary between patients.

Poor or exclusivist approaches to breast cancer communication are often not due to a lack of care or concern by health care professionals or systems. Rather, there is an acknowledgement that effective and inclusive approaches to cancer communication are part of a large, dynamic and complex gauntlet. Navigating its complexities is difficult, requiring extensive investigation and resource application. With evidence showing poor communication issues being linked with anxiety, depression and anger (Rees et al., 1999), addressing ways to improve cancer communication is likely to improve the effectiveness of the entire clinical encounter, for both patient and provider.

### **1.15 Communication Needs of Breast Cancer Patients**

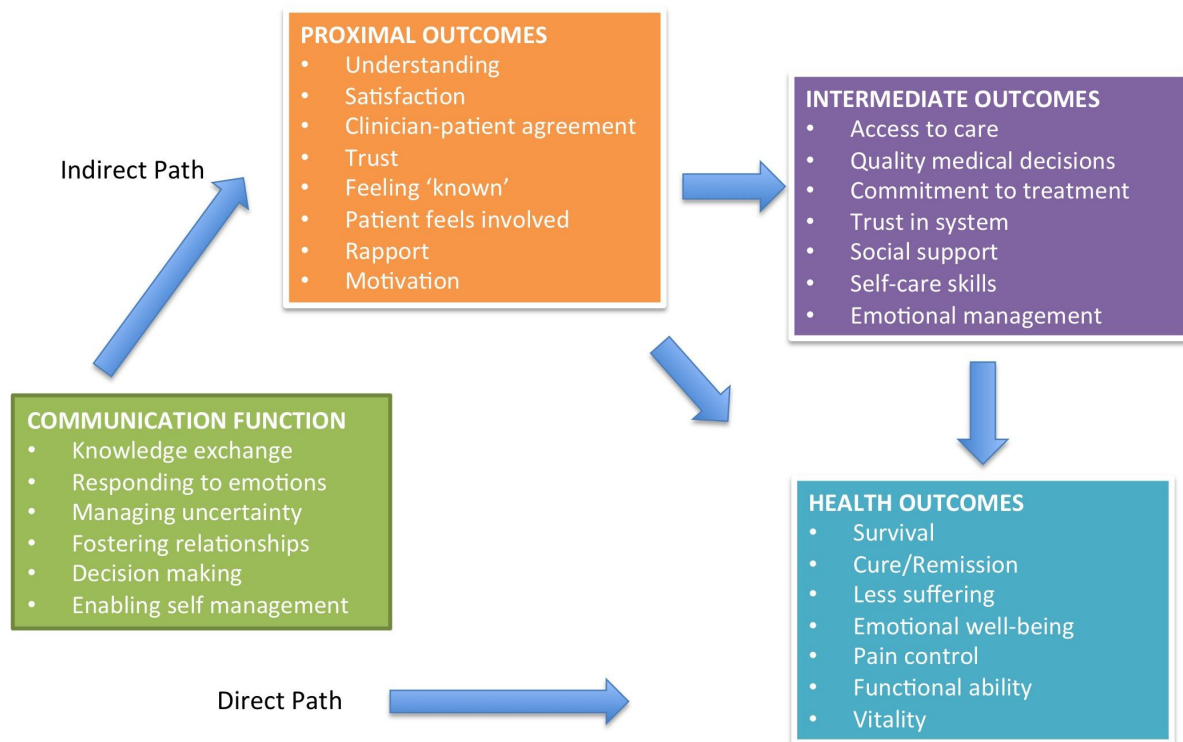
There is a role of improved communication in optimal cancer care provision (Thorne et al., 2005). The absence of good communication, or dissemination of information in an exclusivist or limited fashion, ultimately provides a disservice to patients during their treatment pathway, with information being recognised as a necessary prerequisite to informed decision-making (Cawley et al., 1990), that can aid coping (Rees et al., 1999). However, with the informational needs of patients changing over time (Luker et al., 1996) a dynamic approach is warranted.

Street et al., (2009) discuss how clinician–patient communication can help predict health outcomes weeks and months after the consultation, although they acknowledge the specific mechanisms accounting for these findings are poorly understood. Best outcomes from effective knowledge exchange include patient understanding, trust, and clinician–patient agreement (Ha and Longnecker, 2010). These affect the intermediate pathway where treatment decision making comes into play, which ultimately leads to

increased adherence to treatment and improved self-care skills that, in turn, affect the patient's overall health and well-being.

Fogarty et al., (1999) state that even general conversation can be therapeutic for a patient if their physician uses it to validate the patient's perspective or express empathy. This in turn can improve the patient's psychological state, reduce fear and anxiety and evoke feelings of hope, optimism, and self-worth (Fogarty et al., 1999, Ong et al., 2000 and Schofield et al., 2003). Even nonverbal communication cues such as touch or tone of voice, can improve well-being by reducing anxiety or providing comfort as discussed by (Henricson et al., 2008; Knowlton et al., 2006 and Weze et al., 2004). There are multiple pathways through which communication between patients and medical professionals/caregivers can influence health outcomes as outlined below (Figure 1.4).

Griffin et al., (2004) also lists seven pathways through which communication can lead to better health for patients. These include: better care access; increased knowledge exchange and mutual understanding; improved medical decision-making; enhanced therapeutic relationships; healthier social support; and improved patient empowerment and emotional management of their cancer experience.



*Figure 1.4 Direct & Indirect Pathways from Communication to Health Outcomes. Retrieved from: Street et al., 2009.*

### 1.16 Current Campaigns: Social Inclusion

The term 'social inclusion' portrays a society, which fosters engagement and allows room for diversity. But in order to achieve this ideal, the voices of people and their needs and concerns, must be heard (United Nations: DESA (2009). Delivering a message effectively by relying on traditional images can and often does clash with the obligation to promote inclusivity as part of a human rights approach. This is evident in current communication methods in New Zealand, with much of the online breast cancer support content saturated in pink and imagery of post-menopausal women. Information pertaining to the atypical was often buried, relegated under a small heading to the side of the page or within a small passage of information in the resource. See the following (Figures 1.5 – 1.8) which show how to navigate to information on 'Male Breast Cancer' on the Breast Cancer Foundation website.

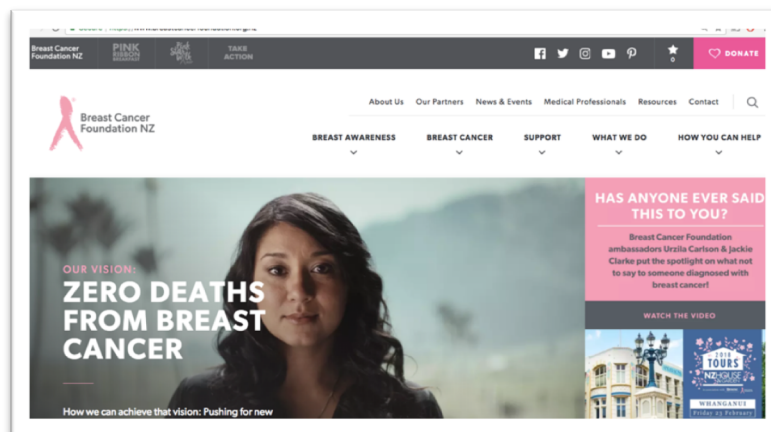


Figure 1.5 Step 1 - How to get to information on 'Male Breast Cancer' on the Breast Cancer Foundation website (<https://www.breastcancerfoundation.org.nz/breast-cancer/types-of-breast-cancer/breast-cancer-in-men>. Retrieved 15th February 2018).

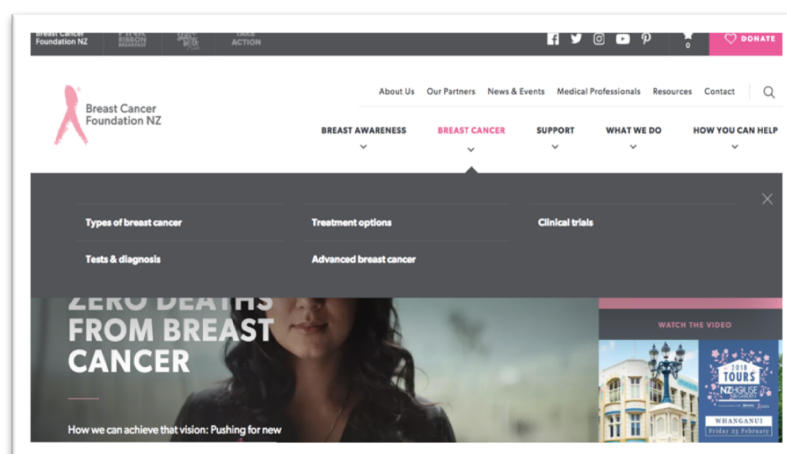


Figure 1.6 Step 2 - How to get to information on 'Male Breast Cancer' on the Breast Cancer Foundation website (<https://www.breastcancerfoundation.org.nz/breast-cancer/types-of-breast-cancer/breast-cancer-in-men>. Retrieved 15th February 2018).

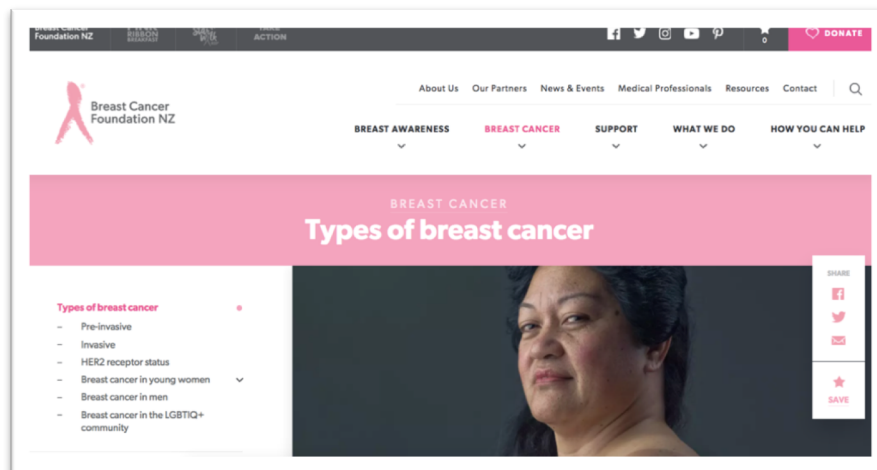


Figure 1.7 Step 3 - How to get to information on 'Male Breast Cancer' on the Breast Cancer Foundation website (<https://www.breastcancerfoundation.org.nz/breast-cancer/types-of-breast-cancer/breast-cancer-in-men>. Retrieved 15th February 2018).

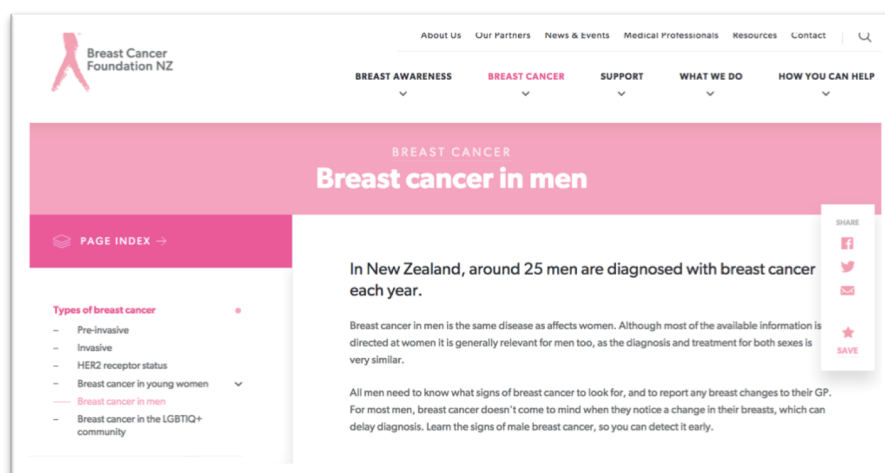


Figure 1.8 Step 4 - How to get to information on 'Male Breast Cancer' on the Breast Cancer Foundation website (<https://www.breastcancerfoundation.org.nz/breast-cancer/types-of-breast-cancer/breast-cancer-in-men>. Retrieved 15th February 2018).

When considering how to target communication to specific population demographics, certain parameters must be applied. This process usually includes a moral judgment which takes into account notions of both equity and utility (Rothschild, 2001). However, the outcome of this approach is that groups can be unintentionally excluded because they are 'hard to reach' or a lower priority (Guttman & Salmon, 2004). The result of this is an atypical or anomalous demographic that the communication is not designed to reach.

This is particularly relevant when reviewing breast cancer communication. Whilst it may be argued that current communication methods are best aimed at the majority of breast cancer sufferers (Rose, 1981), small changes in the inclusivity of effective communication methods can provide improved public health outcomes, even in populations who are at more risk (McLeroy et al., 1995). By including broader segments of the population in the overall message, campaigns can promote values of solidarity, thus reducing the likelihood of stigmatization and the labelling of those considered 'high risk' (Beauchamp, 1988). Alternatively, it may be decided to specifically target the atypical, or those identified as 'high risk' or with particular needs, values, beliefs, or communication channels (Guttman & Salmon, 2004). This could provide an opportunity to observe potential improvements in outcomes for patients.

Despite the arguments for targeting most current communication methods at the majority, i.e. those patients who can best benefit from the information, the same principles must also be used to target the minority. With cancer statistics increasing, the numbers of anomalies who fall outside of the current communication perimeters will increase. This poses the challenge to develop materials that are respectful and not condescending but effective in their format (Guttman & Salmon, 2004) and provide an inclusive, rather than an exclusive experience.





### 1.17.1 Age

A breast cancer diagnosis can be devastating for patients of any age, however there are many specific issues and communication barriers faced by pre-menopausal, young adults with breast cancer. These include: undertaking treatments that may precipitate premature menopause and infertility; undergoing procedures that may affect body image and sexuality; the challenges of caring for young children whilst having treatment; the potential impact of the diagnosis and treatment on employment status and on relationships with partners (Thewes et al., 2004). Gray et al., (2005) noted and highlighted that pre-menopausal patients request more information than post-menopausal patients, that their informational requirements are dynamic and change over time, and that young patients requested support be provided for their families and care givers as well.

It is important to factor young adults into current breast cancer health promotion, particularly during adolescence. If young adults form healthy habits early, they are more likely to maintain them through adulthood and to know how to minimise their risk for preventable health issues (Bailey et al., 2013). The use of technology-based health promotion approaches among youth has been particularly encouraged due to technology's reach and popularity with this age group and is seen as a 'new channel' for behaviour change (Cullen et al., 2013). Research has shown that young people tend to prefer support from informal sources (Collin et al., 2011). They are therefore likely to be open to technology-based approaches. These approaches enable youth to seek help anonymously and autonomously, which can be advantageous to young people seeking help for sensitive health topics or stigmatised behaviours (Khadjesari et al., 2011), and those who prefer self-help, particularly males (Ellis et al., 2013).

A study conducted in the Journal of Surgical Research showed the prognosis for the five-year survival of young patients was severely reduced when compared to that of older patients (74.3% vs. 85.1%). Young patients were found to present with more progressed stages of the disease, with increased tumour characteristics that were found

to be more aggressive (i.e. higher-grade tumours and more estrogen/progesterone receptor-negative tumours) (Maggard et al., 2003).

A number of studies have shown that younger cancer survivors experience more persistent physical symptoms and psychological distress than their older counterparts (Mao et al., 2007). Many young patients also reported that they felt their needs were unmet within the context of their cancer treatment pathway (Hewitt et al., 2007). With young adults being more vocal about their dissatisfaction with existing survivorship care, often having larger familial and financial demands, and an increased desire to be more proactive in their survivorship experience (Hewitt et al., 2007), it is of particular importance that further work in this area be investigated.

### **1.17.2 Gender**

With the strong stereo-typing of much breast cancer communication, men and others who do not relate to the pink, feminine nature of the communication can feel excluded. Gender is an important basic human variable that affects health and illness throughout life (Witzemann, 2001). Gender influences not only reproductive organs and bodies but also in the way people think, feel, and behave. Genes and biology influence the physical attributes of sex; the psychological counterpart, in which environmental, cultural, and psychosocial factors also have a significant role, is gender. Researchers are beginning to unravel the complex interactions between sex and gender, and the roles of nature and nurture are unclear (Kiss & Siegfried, 2001).

Gender disparities become evident not only in the physical impact but also on sex, quality of life, psychosocial differences, coping, and patients' partners. A cancer diagnosis is distressing and approximately 20% and 30% of cancer patients continue to display symptoms of anxiety or depression six months after diagnosis (Nordin et al., 2001). However, depression is often considered incompatible with many core masculinity traits. Societal expectations are for men to be the strong, silent type, with restricted expressions of emotions. They are expected to be tough, self-sufficient, powerful and successful which are contradictory to the real symptoms often

experienced by patients during and after their cancer experience (Kiss & Siegfried, 2001).

Men are less likely to admit to pain or seek health advice, which can result in poor health-care use (Smith et al., 2006; Mellor et al., 2012; Courtenay, 2000). This delay in male help-seeking behaviours can be due to the influence of cultural stereotypes. Men are often said to respond to physical or mental symptoms by using strategies such as denial and a 'toughen-up' attitude that suggests they just need to 'shake it off' rather than seeking health advice or health care (Smith, 2007; Mellor et al., 2012).

Clinicians involved in psychosocial research in cancer think that gender affects how people cope with cancer (Volkers, 1999) but there is little empirical research on this issue. Studies show most men with prostate cancer avoided disclosure about their illness and rather, placed a greater weight on maintaining a 'normal' life (Gray et al., 2000). The reasons for males not wanting to disclose their illness related to men's low perceived need for support, a fear of stigmatization, the need to minimize illness to aid coping, practical requirements in their places of work and the desire to prevent being a burden to others (Gray et al., 2000). Partners are the most important emotional and social support for cancer patients (Baider et al., 1996).

To support and care for others is a fundamental feature of female but not necessarily male gender identity. One study found that female partners possessed a better understanding of their husband's experience with prostate cancer than male partners had of women's breast cancer experience (Carlson et al., 2001). In one of the few studies comparing psychological distress of patients with prostate cancer and their wives, the wives were more distressed than the husbands (Kornblith et al., 1994).

### **1.17.3 Culture**

Indigenous peoples have faced social exclusion and marginalization and their levels of access to adequate health and education services are often below national averages (United Nations: DESA (2009). Indigenous populations are often disproportionately

represented among the poor and extremely poor. Early studies conducted in relation to effective intercultural communication to indigenous groups show a critical need to establish and maintain favourable knowledge exchange and relationships between patients and their caregivers (Dodd, 1995). Medical professionals and support service providers must be able to meet their patients' needs relating to the additional challenges presented via language barriers, unfamiliar customs and practices, and cultural variations in verbal and non-verbal communication styles in order to achieve successful intercultural understanding (Dodd, 1995; Gudykunst & Hammer, 1988).

This literature review shows communication with culturally different patients can often be associated with negative emotional responses (Neuliep & McCroskey, 1997), with patients reporting feelings of anxiety and awkwardness when interacting with caregivers from different cultural backgrounds (Stephan & Stephan, 1985). This was attributable in part to communication obstacles. Intercultural encounters may also be confusing due to group differences in emotional expressivity and non-verbal communication styles (Kim, 1986). Cultural variations in values, norms, and customs may lead to cultural misunderstandings and instances of communication breakdown that are stressful and unpleasant (Giles & Robinson, 1990).

Ultimately, repeated communication failures and misunderstandings can give rise to a negative orientation toward those of different cultures. Studies reviewed show effective doctor-patient communication should include helpful conversation and mutual understanding of the patient's pre-conceived ideas and perspectives (Ha & Longnecker, 2010). Striving to comprehend situations from another's perspective, despite one's own beliefs allows for a more open and positive communication approach (Feudtner, 2007).

Literature shows that culture provides correlated perceptions of self-efficacy and health-related well-being (Warren, et al., 2010), but the beliefs and attitudes that affect behaviour towards health are shown to differ, based on race or ethnicity (Hovick, 2016). Current interventions have been designed in a way so as to increase cancer awareness and address disparities, particularly among minority populations (Hovick, 2016) but

more needs to be done on the effect of race and or ethnicity on belief systems and their impact on health behaviours.

Hovick and Holt's (2016) study found that health communication campaigns that took ethnic identity into account were more effective. Their research highlighted the positive effects ethnic identity had on the health of their participants. They concluded therefore, that campaigns appealing to ethnic identity can be effective for stimulating behaviour change. The limitations of their study, however, was that the cohorts were classified as whites, hispanic and blacks, therefore their results may not necessarily translate to the Māori and Pacifica experience. Also, many of the measures were self-reported and too brief to fully evaluate their hypotheses. Further studies to explore Māori and Pacifica cultural beliefs and attitudes towards breast cancer behaviours would provide considerable insight into how to better address these issues in cancer communication moving forward.

#### **1.17.4 High Risk Patients**

Most cancer patients want to know if they have cancer, their treatment options, the side effects and their overall prognosis (Meredith et al., 1996). However, there is a small minority of patients who do not wish to know. These are most likely to be elderly, those with a poor prognosis or those who come from deprived areas (Maguire, 1999). Patients who may be vulnerable were identified as those with: hearing, speech, or cognitive disabilities; limited access to communication tools and supports; linguistic or cultural differences; limited health literacy, reading or writing skills; and disease, illness, accident or event related communication difficulties (Pressman and Blackstone, 2010). Pressman and Blackstone (2010) highlighted additional difficulties and barriers faced by 'communication vulnerable' or high-risk patients in relation to their medical and treatment outcomes (Table 1).

Doctor-patient relationships and subsequent interactions during the treatment pathway are largely affected by the patients' values and beliefs (Tongue et al., 2009). Studies show that conflicting beliefs can affect health care through conflicting therapies and fear

or distrust of the health care system (Diette & Rand, 2007). This ‘perception gap’ may adversely affect treatment decision-making and thus negatively influence the patient’s outcomes, despite appropriate treatment (Platt & Keating, 2007). Despite doctors’ application of a biomedical model to recognise and treat illness, patients’ beliefs are more influenced by social and behavioural factors (Platt & Keating, 2007).

*Table 1 Outcomes for High Risk or 'Communication Vulnerable' Patients. (Pressman and Blackstone, 2010.)*

More Likely To:	Less Likely To:
Be hospitalized	Adhere to recommended medication regime
Experience medical/physical harm, e.g., drug complications	Report abuse
Leave hospital against medical advice	Access and use medical care
Delay care	Return for follow-up appointments after Emergency Room visits
Receive a diagnosis of psychopathology	Be satisfied with care

Ferrell et al., (1995) applied methods to gauge the quality of life for breast cancer survivors. These were then placed into four principal areas of well-being: physical, psychological, spiritual and social. These are areas which have been shown to be adversely affected in ‘high-risk’ patients. With health care providers providing the principal source of communication and knowledge exchange to their patients, thus largely assisting their decision-making ability (Maly, 2015), poor communication to this demographic can be a barrier to achieving better quality of life (Silliman, et al., 1998).

To ensure high-risk patient adhere to treatment pathways, communication barriers must be identified early and the benefits and importance of treatment stressed and understood (Platt & Keating, 2007). Patients adapt their treatment adherence according to personal worldviews and social contexts, which can result in a conflicting expectation of adherence practice (Sawyer & Aroni, 2003). Good doctor-patient communication is an effective instrument that can be used to understand the patient's expectations and experiences that shape their worldview (Minhas, 2007). With a collaborative communication approach, detrimental or conflicting perspectives are more likely to be identified, allowing for a view from a different perspective and ultimately creating the opportunity for improved assessment and subsequent treatment (Feudtner, 2007).

### **1.17.5 Clinical and Psychosocial Outcomes**

One of the most commonly documented associations in relation to communication outcomes is a correlation between poor communication and reduced patient satisfaction (Ong et al., 2000 and Zachariae et al., 2003). Further, the fear and anxiety incurred in patients who have experienced poor communication is believed to have led to further demands upon the system in terms of the time and effort required to counteract the resultant emotional distress and misinformation it causes (Humphreys, 2000). Thorne et al., (2005) associates poor communication with a number of untoward psychosocial consequences for cancer patients. These include heightened anxiety and depression (Ellis and Tattersall, 1999), poor psychological adjustment (Bishara et al., 1997), ineffective coping (Finset et al., 1997), hopelessness (Sardell & Trierweiler, 1993), and reduced quality of life (Ong et al., 2000).

Psychological distress is often discounted as a normal consequence of having cancer (Fallowfield et al., 2001), which can result in patients not receiving the appropriate treatments for their mental health. In a study by Maguire et al., (1980), training specialist nurses to recognise and refer patients who developed psychiatric problems after mastectomy substantially reduced psychological morbidity. However, a later study found that radio-oncologists' recommendation for supportive counselling did not correlate with patient distress or the amount of perceived social support by patients but



rather with progressive disease and less denial behaviour (Sollner et al., 2001). Oncologists are increasingly aware of the importance communication skills and training has on their ability to detect and treat psychological distress (Maguire et al., 1996).

### **1.17.6 Empowering Processes and Outcomes**

Clinicians who lack training in communication can have difficulty recognizing and responding to patients' ongoing informational and emotional needs resulting in a negative patient perception of the competence and effectiveness of clinicians within the cancer care team (Levit et al., 2013). The doctor-patient interaction is invariably complex and patients are increasingly recognising that they are not just passive recipients in the communication process (Lee et al., 2003). However, miscommunication is a hazard, especially in terms of patients' understanding of their prognosis, expectations and involvement in knowledge exchange and treatment (Baile et al., 2000). Unlike negotiation or mediation, discussion allows a focus on establishing trust amongst groups grounded in different values and culture. Therefore, providing the foundation for participatory dialogue can be an effective tool for fostering positive relationships and common understandings (United Nations, 2007).

Not all doctors are born great communicators. As they progress to specialist level, they must become willing to self-regulate their communication style and seek additional communication training (Roter et al., 2002). Patients and clinicians must seek a reciprocal and dynamic relationship in order to facilitate effective knowledge exchange and collaborative communication (Feudtner et al., 2007). This positive knowledge exchange will ensure that patient concerns are raised and addressed, that treatment options are sufficiently understood and that shared decision making is facilitated (Arora, 2003).

Patients' care pathways need to effectively incorporate expectations, desired outcomes, risk acceptance, and any associated cost to ensure an optimal outcome (DiMatteo, 1998). With most complaints about doctors being related to issues of communication, not clinical competency (Tongue et al., 2005) clinicians who work to improve their

communication and interpersonal skills, will be equipped to provide better support to their patients. This can lead to improved outcomes, increased satisfaction, a reduction in the costs of care, improved information exchange and patient knowledge of health issues, and enhanced adherence to the treatment process (Clack et al., 2004).

On the basis of a review of the literature and with the recommendation of a panel of doctors and cancer patients, Girghis and Sanson-Fisher (1995) created a set of standards on how to deliver bad news to patients. These included the need to: ensure adequate privacy and time; assess patients' understanding and/or preconceived notions; be simple and honest about diagnosis and prognosis; encourage patients to express their feelings/concerns; be empathetic; give a broad but realistic time frame concerning prognosis and arrange follow up. Empowered patients are more likely to be successful in managing their condition, collaborating with their healthcare providers, maintaining their health functioning, and accessing appropriate and quality care (Hibbard et al., 2004).

## **1.18 Conclusion**

Reducing discrimination based on attributes such as gender, age and ethnicity can lead to feelings of protection and empowerment of vulnerable and marginalized members of society. This can lead to improvements in social inclusion and the reduction of communication barriers (United Nations: DESA (2009). Although it is well recognized that cancer represents a crisis in the lives of those affected, there are aspects of the crisis that can be prevented or ameliorated. The negative consequences of poor communication are broad and substantial in scope. Furthermore, poor communication exerts economic, social, psychological, emotional and collateral costs to the patient, the patient's support network, the clinicians, the cancer care system, and society itself (Thorne et al., 2005).

There is a clear need for the medical sector to continue addressing communication barriers as an integral part of the cancer treatment pathway, moving forward. Research

shows clear links between patients who received poor, misdirected or ineffective communication with poorer psychosocial and clinical outcomes. This thesis aims to contribute to current knowledge and the ongoing dialogue about cancer care communication and delivery, especially with regard to identifying areas where there may be issues of exclusion or poor communication. Inclusive communication in cancer care is at the very core of the agenda to improve patient outcomes. While the financial implications of the creation of inclusive societies can be challenging, the results are ultimately beneficial to all (United Nations: DESA (2009)).

### **1.18.1 Research Questions**

This study contributes by examining perspectives of health care professionals at the front line of communication with breast cancer patients. Specifically, this study explores important categories of anomalous patients in the local context through thematic content analysis of interview data from health practitioners. This chapter has reviewed literature that relates to patient efficacy, perceptions, vulnerabilities and behaviours relating to communication experiences during the cancer pathway, with a focus on the atypical experience.

The next chapter describes the research methodology used to explore health practitioner perspectives. Through in-depth face to face interviews, I addressed the following research questions:

1. What are health practitioners' perspectives about communication with breast cancer patients in New Zealand?
2. What are health practitioners' perspectives about communication with atypical breast cancer patients in New Zealand?
3. Are there differences (and/or should there be) in the approaches to communication with atypical patients?
4. What are barriers to effective communication and knowledge exchange between patients and medical and support service providers in New Zealand?

5. What recommendations do health practitioners have that might improve communication with breast cancer patients, particularly with atypical patients?

## **CHAPTER TWO: METHODOLOGY**

### **2.1 Research Design**

A qualitative research design was used in order to explore participant perspectives in depth and without the limitations of an existing framework (Creswell, 2013). Knowledge gained from an exploratory study can be used in the design of follow-up research projects, potentially applied to larger populations (Merriam 2009).

An exploratory case study approach was selected as such studies have been successfully applied across the social sciences (Cassel & Symon, 2004). This was an appropriate approach for the exploratory and descriptive nature of my research, allowing for participants' individual perspectives to be investigated in depth (Kvale & Brinkman, 2009). The interview process provided the opportunity to understand participants' answers contextually, probe interesting thoughts and seek further clarification if required (Merriam, 2009).

The locale for this research was Dunedin, New Zealand. The assistance and cooperation of the Otago office of The Cancer Society contributed to access of participants, as did the Otago District Health Board and Dunedin Hospital, a recognised national teaching and Oncology specialist centre.

### **2.2 Data Collection**

#### **2.2.1 Recruitment**

Approval for this research was granted by The University of Otago Ethics Office (Reference number D16/265) in September 2016. The participant employment spread is referenced below (Table 2). The Cancer Society assisted in the recruitment of participants for this study by identifying potential health professionals and service providers suitable for in-depth, face-to-face interviews. This initiated a snowball

method of recruitment whereby participants were asked to recommend others for interviews. An information sheet was provided to potential participants via email or in person. If the potential participant agreed to participate, they were asked to provide me with their contact details.

The Health and Support Service professionals interviewed were asked if they could identify others who might be willing to discuss their breast cancer communication experiences with atypical patients in an interview and an invitation was included on the information sheet to contact either myself or my supervisor Professor Nancy Longnecker, in order to participate.

Table 2 Employment Spread of Interview Participants

Participant ID (P)	District Health Board (DHB)	Non-Government Organisation (NGO)	Private Practice	Years working with cancer patients	Role (specialist / support/coordinator)	Area of specialty
P1		•		7	Support	Survivorship
P2		•		6	Support	Gender / Survivorship
P3	•			20+	Coordinator	High Risk
P4	•			9	Coordinator	Young Adults
P5	•		•	2	Specialist	Survivorship
P6	•			16	Specialist	Treatment
P7	•			20+	Specialist	Treatment
P8		•	•	40+	Support	Survivorship
P9	•			9	Specialist	Treatment
P10	•			14	Specialist	Young Adults
P11	•			14+	Specialist	Treatment

### 2.2.2 Interviews

Semi-structured interviews were conducted in Dunedin, Otago, New Zealand between July and October 2016. Eleven participants gave in-depth interviews (ranging from 20 to 60 minutes long) about their professional experience with breast cancer communication dissemination in New Zealand. Participants included support service professionals, registered nurses, breast cancer co-ordinators, breast surgeons, medical oncologists, cancer care co-ordinators and clinical psychologists. Participants worked for the District Health Board (hospital), non-government organisations and in private practice (Table 2). Each participant was asked the same set of open-ended questions, which were designed to encourage a good sense of the participants' feelings, attitudes and personal perceptions in relation to the research questions (Braun & Clarke, 2006). Specific questions posed in the semi-structured interviews were based around the research questions listed in Chapter 1.

Participants answered questions about their professional experience with breast cancer communication dissemination in New Zealand (Table 3). Nine of the interviews were face-to-face and two via Skype (**P7** and **P10**). There were issues with the Skype calls dropping out on both occasions. **P7** had a very limited timeframe in which to conduct the interview. **P10** and I agreed to conduct the remainder of the interview over a speakerphone, with the sound recording device placed next to it. The different mode of capture did not compromise my ability to transcribe the recording.



*Table 3 Questions Posed in Semi-Structured Interviews*

1	How long have you worked with breast cancer patients?
2	In what capacity?
3	How do you find communicating about breast cancer and treatment with patients?
4	How do you find communicating about breast cancer and treatment with atypical patients?
5	Do you think there are any barriers in communicating specifically with atypical breast cancer patients?
6	Are there any differences you might employ when communicating with atypical patients as opposed to a non-atypical patient?
7	How do you find communicating about breast cancer and treatment with carers/family members?
8	How do patients and/or carers respond when communicating about breast cancer and treatment? (i.e. focusing on effective knowledge exchange)
9	Do you have any recommendations for health care providers or for patients that could improve communication during breast cancer diagnosis and treatment; and
10	Do you have any other comments that you'd like to make?

All participants were provided with a Participant Information Sheet (Appendix IV) and Participant Consent form (Appendix V) to sign and return before any interview questions were asked. Most of the interviews lasted approximately 20 to 60 minutes. The participants were all asked the same set of questions, although the order and depth of discussion around the topics varied, as determined by the flow of the interview. The participants were told of the topic of the interview, but a copy of the questions was not

provided to them beforehand to ensure the extemporaneous nature of their responses (Kvale & Brinkman, 2009).

A brief background to the study was given at the start of each interview (Appendix III-i). At no time were participants made aware of my own experience with breast cancer. Participants were asked for permission before audio recording took place and they were informed that the sound files and interview transcripts would be de-identified and kept confidential. Each participant was reminded that their signed consent form reinforced their anonymity and that they could withdraw from the study at any time without prejudice.

Throughout the interview, care was taken to be consistent in phrasing, sentence structure, facial expressions and body language. The questions were delivered in much the same order, unless the participant steered the conversation towards a specific question. If any participant needed clarification of a question, I rephrased or explained, attempting to maintain consistency between interviews. Interviewees were encouraged to discuss issues important to them, which successfully allowed the themes to emerge (Burchell et al, 2009). To support this conversational style, I asked questions as the topics came up, rather than directly reading from a questionnaire. This supported a conversational flow and encouraged a trusting exchange between the participants and myself as the researcher.

### **2.2.3 Limitations and Insider Research**

Researchers view and interpret data through their own experiences (O’Leary, 2004). I have had a strong interest in pursuing this topic for several years now. It was my intention to conduct research in an area that relates to atypical cancer patients, with the hope this research would improve experiences of others along the cancer journey. Whilst it was my personal experience that shaped the desire to undertake this exploratory study, the potential for bias in the questioning and in analysis of participant responses was carefully considered and attempts were made to maintain objectivity throughout the process.

My supervisor acknowledged the possibility for negative feelings to surface during this study, given my personal breast cancer experience. Therefore, we met regularly in order to debrief and discuss the study and any negative feelings throughout. Professor Longnecker, being a step removed because of not having had breast cancer, served as a foil during data analysis.

### 2.2.4 Transcripts

The researcher was mindful that each interview be conducted consistently. The same approach was applied to the transcription process. When possible, the audio recordings of the interviews were transcribed within 48 hours of the interview. This was to ensure the content was fresh and the nuances and context could be accurately annotated. Recordings were repeatedly listened to during analysis to ensure accuracy of the transcript, to allow the data to become familiar and to minimise potential bias from the researcher's insider perspective.

Comments from participants are identified with a 'P' and numbered chronologically, according to the interview date. In order to ensure a smooth transition from oral delivery to typed transcription, repetitive words, pauses, stutters and gaps were removed. For example, the original transcript read:

*I think talking about uh, sort of positive people out there who are the atypical is really good, um it just helps. I think people my age don't want to think they could get something that is life threatening so they block it out, so I think you need positive stories out there so people won't be scared and they'll go "oh well, I'll just go and get a check" because it will be part of the norm. (P2)*

The edited version reads:

*I think talking about positive people who are the atypical is really good, it just helps. I think people my age don't want to think they could get something that is life threatening so they block it out. I think you need*

*positive stories out there [so] people won't be scared and they'll go "oh well, I'll just go and get a check" because it will be part of the norm. (P2)*

Once the interviews had been transcribed and recurring themes that described important aspects relevant to the research question began to emerge (Braun & Clarke, 2006), notes were consolidated into a spreadsheet along with quotes that could be used in reporting the results.

### **2.2.5 Transcription Summary**

A summary of the interview including quotes that might be used was emailed to each interviewee to check for accuracy (Lincoln & Guba, 1985). In the email accompanying their summary, participants were asked if they would like to add any additional information or withdraw the use of any of the information or quotes derived from their interviews. Minimal responses or corrections were requested, for example:

*My only change would be to do with this paragraph: "We have an 'end of life' document that's come from the lawyers for young people to sort of talk about their wishes... if they couldn't make decisions for themselves... so at the moment we're using the US one where we would love to make a New Zealand sort of version... but once again, funding and time...". Can you change it to: "we have an 'end of life' document that's come from research done with young people in the United States which helps young people to talk about their wishes... if they couldn't make decisions for themselves... so at the moment we're using the US one where we would love to make a New Zealand sort of version... but once again, funding and time. (P10)*

*I removed the (\*removed) episode as I think he could be identified. I removed localities, for the same reason. (P5)*

*I am just a bit nervous that this might make my participant a bit more obvious as he is in a small group. I am happy for you to use the first half though if that helps. (P2)*

All changes or recommendations were made to the data in the process of member-checking.

## **2.3 Data Analysis**

The coding was inductive and data driven, rather than pre-emptive or concept driven (Thomas, 2006). Coding categories were not created prior to the interviews taking place, as these may not have accurately represented the themes that emerged from the narrative of participant's experiences. Instead, thematic categories were selected after the conclusion of the interviews and after transcription, analysis and discussion of the data.

The original data collected (voice recordings) were securely stored on a hard drive in a locked office in the Centre for Science Communication, with access available only to the researchers. Identifying details were stripped from the data files for use in data analysis. The files were then uploaded to the University's secure server (Syncplicity), again with access available only to the researchers. Data files will be retained for at least five years.

Repetitive reading and coding of the interview transcripts familiarised me enough with the content to make provisional sense of the collective data. Analysis was primarily inductive (Braun & Clarke, 2006; Thomas, 2006) and common thematic categories that emerged across the interviews were identified. Analysis was guided to some extent by my prior understanding and tacit knowledge of the scientific context in which interviewees work, as well as my awareness of the issues that were likely to be raised and views about the public that are typical to the discipline. Some studies have shown that familiarity with the interview subject matter can make analysis of interviewee

responses easier (Coar & Sim, 2006; Hewitt, 2007). Interview responses are quoted verbatim in the results and discussion chapter.

### **2.3.1 Categories**

The content analysis of the qualitative data collated for this research allowed a narrative to emerge from the interview participants' stories and experiences. From their descriptions of what happened when, to whom, and with what consequences (Patton, 2005), the interview participants' stories clarified the processes and outcomes for atypical patients through the eyes of the medical and support services professionals. This makes the findings both valuable and credible.

### **2.3.2 Coding**

Content analysis encourages a key pattern to emerge for interpretive coding purposes. This approach allows the researcher to extrapolate the underlying themes in the data that relate to the significant aspects relevant to the research questions (Boyatzis, 1998). Merriam (2009) recommended the adherence to four rules when developing these themes or categories. Firstly, that the name given to the theme be "sensitive" to the data, yet descriptive enough for other researchers to obtain the same denotation. Secondly, that the themes should be "exhaustive", incorporating all of the significant data. Thirdly, that the themes should be "mutually exclusive" so as to provide clarity under which heading data should be placed and finally, that all themes be "conceptually congruent" so as to provide consistency (Merriam, 2009).

The qualitative data obtained from the interviews were analysed and sorted into key categories relating to the research aims and questions. The categories that emerged were Age, Gender, Culture, High-Risk and Survivorship (Table 4). The titles of the categories are appropriately descriptive of the data, in line with Merriam's (2009) first rule.

The main findings were then summarised into paragraphs along with important quotes that supported the themes. To reduce bias and monitor the internal validity of the research, a coding manual was created to describe each category (Table 5).

Interviews of each of the eleven participants were coded against the category headings and illustrative quotes were noted. Because of the semi-structured nature of the interviews, each interview was examined in its entirety. Using the coding manual, another science communication researcher and I reviewed excerpts from the transcripts, coded them in the categories and then compared the results. Calculation of inter-coder reliability gave a result of 93%.

Table 4 Categories from Participant Interviews (n=11)

Category	Number of Participants who mentioned this topic in Interview	Examples from Interviews
Age	8	<p>"I think it's an invincibility thing... Unless you've experienced it in your own world, in someone young, I don't think you think it will happen"</p> <p>"It's really important to spend time one on one with a young person and then bring in more staff as a group, or their parents, or support person"</p> <p>"He's there because he hasn't got support anywhere. He's there because he's frightened"</p>
Gender	7	<p>"From what I learnt, it was always Stage 3 or 4, when men were diagnosed, because they're like "well I can't get breast cancer, I don't have breasts" ..."</p> <p>"It's interesting culturally. It's very different for Māori, because you don't want to be showing your breast, or discussing your breast with the woman who sits in the pew next to you when you go to church... then you know it will be talked about"</p>
Culture	6	<p>"In a Pacifica family, 17 members came into the room to hear what was going on. That's important culturally, from their point of view, so they know what's going on. So, they feel included..."</p> <p>"Who are these people who are getting poorer outcomes and who are getting less support and getting less help? Yes, they are probably not asking, but culturally they won't, or geographically, or financially... For us to be aware... we need to do extra effort"</p>
High-Risk	3	<p>"...self-harming... she had lost her home, she was sleeping on the couches of men friends. We couldn't get her into appointments because we never knew which house she was at..."</p> <p>"The more we discuss and educate people on the side effects, that don't finish after treatment – they can be life long, there's just so many people out there that are just ignorant of what happens when you finish treatment..."</p>
Survivorship	11	<p>"They put all these services in place and then they go "see you later" ... Patients come out of these acute services, someone goes "God I had this massive anxiety attack because there was no one there and I didn't know what to do..."</p>



## CHAPTER THREE: RESULTS AND DISCUSSION

This chapter presents findings from semi-structured interviews with medical and support service professionals who work on the ‘front-line’ of cancer communication in Otago, New Zealand. Every participant interviewed acknowledged the importance of improved communication in general, to the enhancement of the cancer patient pathway.

Participants expressed the importance of reviewing and making recommendations to improve both internal (interdepartmental) and external communication, so as to break down known obstructions to the effective, more holistic treatment of patients in New Zealand. This is imperative as the number of breast cancer diagnoses continues to climb, and along with it, the present and ongoing physical and psychosocial issues surrounding the diagnosis, treatment and survival (Fallowfield, et al., 2014). The review and improvement of current communication methodologies, at the diagnosis stage is highlighted by participant responses. Decision making, by patients and their service providers, even at the diagnostic stage of the breast cancer pathway can affect a patient’s quality of life for decades (Ullman, 2014).

### 3.1 Communication: Barriers and Benefits

Communication needs vary between patients. Participants in this study acknowledged that there are many mitigating factors to take into consideration when assessing patients’ communication needs from a medical and support services viewpoint. For example, who is the patient? Do they have specific cultural needs? Are they supported by friends and family? If not, do they have an advocate? What do they know already? (i.e. what do they already bring into the room), and what are their preconceived notions?

*Communication’s an incredibly varied church... people come with their own experiences, their own expectations and they vary enormously in their needs*

*for information... it ranges from people who are relatively blasé and feel like they have a good grasp of what's going on and they feel like they are going to be well, to the people who are completely terrified and are overwhelmed with the diagnosis, so you have to tailor the communication that you're doing to the patient in front of you. (P6)*

Participants were asked how they find communicating about breast cancer and treatment with patients at diagnosis. It was made clear at the start of the interview that if the question pertained to communication outside of their role, that they could determine their own appropriate response. All of the participants in this study talked openly about their passion for their jobs, their commitment to care for the sick and the importance of doing everything possible to ease suffering.

*It doesn't matter who you are, whether it's a daughter, son, mother you can't take this away. You can't make it different. You can't change it, so how can you help? (P9)*

All participants were positively focused on the importance of effective communication. It was made especially clear that the first interaction with the patient, is the foundation for all further positive connections during that patient's treatment pathway. However, a barrier to that first encounter is sometimes getting access to patients at all. **P1** noted the difficulties associated with being able to physically reach out to patients in the first instance as being problematic.

*We have referrals that come through and those are not automatic. They're either self-referrals or they're referred by an external referrer. So, we don't hit all people that have cancer... The referral pathway's not robust. Why? I'm not quite sure. I think it has something to do with the consent process... it's really difficult to actually get into the hospital... and actually hit on those patients. (P1)*

This means in order to access many of the support services on offer, patients must first make the decision to walk into a support services building and ask for help. **P1** continues explaining how hard this first contact can be, especially in relation to atypical patients who show worse statistics for seeking help in the first place:

*There's that label above the door "cancer" you know? I'd like to take it off. They come in underneath it and it's like, you're wearing this over your head. That's hard enough to face without having to come through that door and say "I have cancer, can I talk to someone?". It takes real self-esteem and courage. The word (cancer) becomes overpowering and it shouldn't because it is just a disease and it is treatable. (P1)*

The question of whether communication styles should be modified when faced with an atypical patient (to take into account their additional issues, i.e. gender, age, culture etc.) upon diagnosis was asked. Of the eleven participants, nine said that they would adapt their style to cater for the additional needs of an atypical patient:

*Oh definitely... they want to be told, "you are a member of the human race, you exist", so the diagnosis, the formulation of a diagnosis and being given that, gives you an identity. So, you have to be very careful about how you use that... when you've got something out of the norm... that's where you're trying to save them, to belong. (P8)*

*I probably would, I have to be honest. I would. For a moment, I'd be a little bit taken aback because it's unusual and then I would probably pay them more attention than I would of a normal breast cancer patient and that's the honest truth. Because I know they wouldn't get that outside of here. (P1)*

Two out of the eleven participants disagreed with changing their communicative style when presented with an atypical patient. One of these aimed to be consistent for all.

*I don't think you should change it at all. I think it stays the same... I don't think we should change how we talk depending on who it is. (P2)*

The other participant who disagreed with changing communication for atypical patients said:

*I don't think there is a 'typical' patient... some people are more disadvantaged than others, but when it comes to a cancer diagnosis I think how the person responds... finds their life unbalanced, quite individually different and I see that in high functioning individuals. That diagnosis can completely uproot their normal life... (P7)*

In addition to each individual being different, the same individual can have different needs during their cancer journey. **P6** particularly noted:

*People recently have talked about pendulums of indecision, when people... will swing back and forth between uncertainty, fear... and at other times being sure where they're at and what they're doing, so it's not a straight forward linear thing in communication. It changes all the time and different things can trigger new anxieties and concerns for some patients. (P6)*

Many of the participants described positive first impressions and rapport-building as one of the biggest facilitators to effective communication and knowledge exchange. In fact, without it, the supportive role can be completely mitigated. **P1** explained:

*Once they go into hard acute treatment, you're told where to go, what to do, you just have your whole life basically formed into a routine that's governed by the acute services. You turn up at this time, you have your chemo, you go away, you may ring the assessment unit because you're not well, and you come back in again and it goes backwards and forwards until you're actually finished treatment. Then you get to the end of it and that's it, you're apparently cured. Hopefully. That's it. Over. Where [do] we fit in? ... we get*

*lost in that acute moment... unless that person is needy and... you've formed a relationship. (P1)*

Three of the NGO participants acknowledged the difficulties aren't always when the patient is in front of them. For many, where the interaction is voluntary and must be instigated by the patient (i.e. in the case of support services outside of the hospital cancer treatment pathway) the difficulty can lie in supporting the cancer patient at all.

**P1** provided some statistics:

*We only service 7% of the population of New Zealand but our geographic spread is 24% of New Zealand... so there are huge anomalies there. (P1)*

## **3.2 Categories**

Through content analysis of the transcribed interviews, five main categories emerged in relation to the major barriers to effective communication and knowledge exchange between atypical patients and practitioners: Age, Culture, Gender, High-Risk patients, and Survivorship (Table 2.3).

As expected, participants whose work focuses on a particular patient group (i.e. a young adult cancer nurse coordinator) tended to make more references to the categories specific to their roles. Each of the categories is examined and discussed in the following sections.

### **3.2.1 Age**

As discussed in Chapter 1, pre-menopausal women have a host of different factors to consider during breast cancer treatment. One of the recurring issues mentioned by participants was the underrepresentation of this demographic in current campaigns:

*All the ads are sort of middle aged women and most of the women I met had young kids... you know they weren't that age... When you look at those pictures on TV, you think well that's not me so don't worry about it. (P2)*

*It's been a real learning curve for me... trying to find the information that's age appropriate and targeted towards young people... It's not really out there... The information is written for adults or written for children. It's not written for teenagers or young adults... I spent quite a lot of time trying to trawl on the internet to find support groups specifically for young women with breast cancer and talking to the breast cancer nurse specialists, you know trying to learn information from them to then deliver it in a youth appropriate language and format. (P10)*

**P2** described hearing young adults expressing feelings that breast cancer is an 'older woman's' disease and that it doesn't pertain to them. **P2** recommended the use of online media and positive role models in society talking about breast cancer in young women as effective tools to modify this way of thinking:

*Things are changing so quickly with social media. Those are really good avenues for getting to younger people. I think talking about positive people out there who are the atypical is really good. It just helps. I think people my age don't want to think they could get something that is life threatening so they block it out. I think if you have positive stories out there... it means that people aren't scared and they'll go 'oh well, I'll just go and get a check' because it will be part of the norm. (P2)*

It was interesting to note that participant **P6** was wary about increasing awareness in young adults in breast cancer campaigns. They described educating the public as a balancing act:

*Putting a campaign out, to say 20-year olds to check their breasts... at what stage do you want to make people anxious about their breasts when in fact*

*their likelihood of getting breast cancer in your twenties is extraordinarily small? But, you don't want them to leave it if they find something... You've got to have the message that if they find something they need to get someone to check it, but in fact most of the time it won't be breast cancer... How you get that message right is a very difficult balance. (P6)*

There are many factors to take into consideration when communicating to a young adult with cancer. **P10** talked about sitting in on a consultation with a young adult and described feeling overwhelmed, even as a support person in that instance:

*I sat through and listened to all the options that she now had to consider because she had completed her chemotherapy and now she's heading for surgery and radiotherapy ... I'm used to hearing huge amounts of information and delivering information but the options and potential things that she had to think about was huge and overwhelming... I came out of it and I said to her "I don't even have words. Like I don't even have words to say to you...because that was just huge. (P10)*

**P6** also made references to the additional stressors facing young adults during the cancer pathway:

*With a younger woman, you are more likely to discuss fertility issues if they haven't yet had their families or yet concluded their families... the way it's going to impact on them from a psychosocial point of view because younger women are more likely to have young families, so having that disruption in their life makes a big difference to how they're going to approach it as opposed to someone in their 60's who might be semi-retired, no children or dependents at home. Those are very different scenarios people have to cope with. (P6)*

Another common perception of participants was the lack of age appropriate resources and tools available for young adults with cancer in New Zealand as highlighted by **P4**, **P6**, **P9** and **P10**:

*It's all about health literacy and designing resources and information and giving information that's youth friendly and that's age and developmentally as right as possible. (P4)*

*We don't have any resources... to give out to young people... We have a specific nurse specialist who looks after very young cancer patients... but that only goes up to the age of 25... but not any other resources above and beyond the norm for women in their 30's and 40's. (P6)*

*It's very, very stressful for the ones that are out of the 'norms' like your younger ladies who have quite often got young children... or are working just to pay the bills. How do they cope?... I don't by any means mean to demean the experience that an older person has. It's still cancer, it's still facing one's mortality but I personally don't find they have as much stress as a younger person. (P9)*

*How can you know they're actually making an informed decision without hearing in their own voices what the information is that's been given? (P10)*

Participants described many of the additional issues young adults face during and after the treatment pathway, including decision making about fertility preservation. **P10** noted that many young adults have not yet given serious thought to starting a family or what it means to have that option taken away via hysterectomy:

*A lot of these young people haven't been in romantic relationships... how do you do that following cancer? How do you share that with a partner? What are the sexual side effects of the treatment that you've had? You know, someone's mentioned that you might have early menopause. Do you*



*actually understand what that means? And if you do want children you potentially want to not wait too long. (P10)*

Other issues discussed within the theme for young adults with cancer related to the following issues: chemotherapy being a visual representation of their cancer (i.e. something they cannot hide from others), decision making around breast reconstruction and mastectomy, body image issues and self-consciousness; and physical and psychological scarring.

**P10** highlighted another stressor particular to this patient demographic worth considering:

*We're designing a survivorship passport for young people so at the end of their treatment we'll do a psychosocial assessment on them, just focused on survivorship... reconnecting them to their GP and also the other care workers around New Zealand in case they go travelling... when you're older, you're likely to have had your personal insurances and that sorted out. Well, young people possibly won't have health insurance or travel insurance or house insurance or life insurance or any of those things yet, or they would have been on their parent's insurance and now that they've had cancer... they're not going to get that covered. (P10)*

All of these additional factors present life-long implications for young adults with breast cancer.

Discussions around this category provided a unanimous view about a need for age appropriate resources, including tools and/or positive role-model campaigns being created to assist and support those responsible for communicating with young adults with breast cancer.

### 3.2.2 Gender

*I mean how do you say, "I have breast cancer" to your mates? That's really difficult... you know the basic New Zealand attitude just is women have breast cancer, but that's not true. Men do too... and that's hard especially if they're the breadwinner and they're at work and then they have to face all that chemo and radiation therapy... and the surgery is just as mutilating. (P1)*

Participants to this study reported that the male experience with breast cancer communication is generally quite poor. Because of societal notions, a female gender media bias and little education about the potential for men to get breast cancer, they discussed how men who do seek treatment are often in later stages of the disease, which has negative implications.

*Not men. Not men at all. And I think it's something that men won't initially think and the doctors won't initially think... from what I learnt it was always Stage 3 / 4 when men were diagnosed because they're like 'well I can't get breast cancer. I don't have breasts'. (P2)*

Participants expressed that despite the rarity of men registering with breast cancer, it is happening and those suffering need to be catered for. Every health professional participant in this study had encountered and cared for males with breast cancer in New Zealand although their recommendations for dealing with this issue varied.

**P3** suggested clinicians could avoid contributing to male cancer patients' feelings of isolation or exclusion by normalising the experience:

*He heard that word cancer and then nothing else. He was middle class, affluent, but once you've got cancer affluence does tend to go out the door... He had an incredibly rare cancer and the last thing you want to hear every time you see a new Doctor is 'ooh I've never come across this cancer before'*

*... you need someone who says 'ok I have heard of this cancer before and you're in safe hands'. (P3)*

**P2** identified additional aspects of isolation for males:

*With women it's that sisterhood, you know? ... if they've had a mastectomy it's fairly common to think they're going to have problems with their femininity afterwards and you know they might struggle with that psychologically... A man can't really talk to his guy mates about how he feels as easily. And if he goes into a support group for breast cancer survivors, it's a whole lot of women talking about that stuff. And in somewhere like Dunedin, there's not enough men diagnosed that they can have all of them in one support group. So that's really hard. (P2)*

**P2** also made comments in reference to current campaigns being exclusive to females, describing male patients saying they felt poorly represented in breast cancer campaigns, in a "pink" world:

*Men are always in those campaigns but it's, 'I'm wearing this for my sister.' It's not, 'I've had breast cancer.' They're always the supporter and that is more likely going to be their role. But that's how we always think of men in a breast cancer arena and it's not always the way. I think the advertising, if you make it all women and all women who are middle aged, it's blocking those others out and it's making it a lot harder for them to accept what's happened and also find support and reach out to get help. (P2)*

**P5** talked about males using coping strategies in line with pre-conceived notions of what society expects of them as a "man":

*I would have a couple of men you know in their 50's, 60's, 70's and they would have one or two polite sessions and then they say 'nah I'm fine'. And so, I leave it with them... I think that for some people it's just very hard to*

*change their style of coping. I usually try to encourage this by saying, 'Ok so you have your coping strategies and they work really well for your life but your situation right now, especially for palliative end of care is huge. It's as huge as crises go'. (P5)*

Some participants described additional factors faced by males with breast cancer, including: embarrassment, feelings of isolation, lack of education, understanding of information, breast reconstruction, mastectomy, body and self-image, physical and psychological scarring, work and financial implications, and being less likely to fit into support groups for women.

### 3.2.3 Māori /Pacifika

Māori and Pacifika patients face a host of cultural and communication barriers to effective knowledge exchange during their cancer pathway.

**P3** reflected on an experience where their support was not considered culturally appropriate by a patient, as the **P3** is Pākehā:

*I worked with a gentleman in \*\*\*\*, I worked with him intensively on the phone. When he met me, I was a disappointment to him. I look like I'm a member of authority and he told me as such. It took me ages to reconnect on the phone so sometimes I think my appearance is a barrier and I will keep it to phone contact as my voice is ok. But my appearance... you just have to test it the whole time. Are you appropriate? (P3)*

Whilst strides have been made to improve the way we communicate to indigenous and ethnic groups, **P6** highlighted that there is still a long way to go:

*When I was going through med school... there wasn't a lot of cultural sensitivity... but there's a lot more significant training on that in the medical curriculum now... You kind of like to flatter yourself that as a New*

*Zealanders you have some insight into that sort of thing. But we don't of course. (P6)*

Several participants explained that cultural barriers can result in poorer outcomes for patients. Especially in geographical areas where there are smaller Māori or Pacifica populations and fewer Māori or Pacifica health professionals, like in the lower half of the South Island.

*27% of the patient load last month was Māori / Pacifica. Considering 11% of the population in our DHB are Māori / Pacifica, yes, it's disproportionate. (P3)*

Participants expressed that medical professionals and support services are aware of these cultural obstacles and often consider them when presented with a patient of ethnicity.

*I think once you've taken in their cultural differences they feel a bit more supported. With a Polynesian, they need that diagnosis in a group, you know, so they're supported. (P1)*

It was noted that the Otago District Health Board has implemented specialists and put structures in place to accommodate Māori and Pacifica patients, with a view to improving their outcomes. However, more education, understanding and resources to this area are needed, as expressed by several participants in this study.

*I use the 'one car in the driveway' technique... it comes from working in the community. If someone's not doing well and they need lots of services all these cars with their logos on the side turn up. Everyone in the community knows there's an issue in that home. That is not appropriate... You've got so many nurses and social workers around that person, who do they bond to? And who do they truly form a trust relationship with? And do we just blur into a mass? My technique has always been one car in the drive. (P3)*

### 3.2.4 Asian

Many Asian medical beliefs and practices differ significantly from Western ones. Providers need to understand and discuss these approaches and methods in order to effectively care for patients in this group (Ngo-Metzger et al., 2003).

**P6** noted an increase of the presentation of patients of Asian ethnicity:

*Increasingly we're seeing a group of first generation New Zealanders of Asian ethnicity who have moved to Central Otago and they again have different cultural needs and different ways of approaching their illness. (P6)*

Asian patients may face educational, cultural and linguistic barriers. **P3** discussed their hospital not having the resources for a full-time translator. They explain how issues relating to privacy can be compromised in communities with a particularly small cultural demographic.

*If we get a translator, often the translator is a member of their community... Do you want the man who works at the chip shop who is now working as a translator... to know your business? (P3)*

**P3** also noted that during the translation process they would speak for several minutes only to have the translator summarise in a brief, truncated sentence. The health practitioner had no way of knowing if all of the information was indeed being effectively verbally communicated to the patient at that time.

*It's a small DHB and you have a very small ethnic group. You're never going to do it right. You can have the best intentions in the world but we can only work with what we've got. So, I think if the healthcare professional's truly going into every contact with the best intent for the patient, that's the most you can hope for. As we sometimes need to use means we know in our heart probably aren't the best and sometimes you might say something that's a*

*paragraph long and the translator says four words and you think 'oh crap.'  
You know? This is not good... (P3)*

### 3.2.5 High Risk Patients

Patients with co-morbidity markers such as alcohol or other drug dependency, mental health issues or who are vulnerable members of society (i.e. sex industry workers, homeless or displaced people or those without any family or other form of support) are considered 'high risk'. These patients are often difficult to support during their cancer treatment, as highlighted by participants during this study. Studies have shown that people with good social support are more observant and responsive to health campaigns designed to increase awareness and preventative health behaviour (Andsager, et al., 2001).

Participants in this study pointed out that high-risk patients rarely attend regular treatment or participate in effective knowledge exchange with medical and social support professionals during their pathway. They often present in the metastasized and terminal stages of their cancers. High-risk patients are identified early by health professionals via: co-morbidity markers (one or more additional diseases), addiction (alcohol or other drug dependency), mental health issues, violence or sexual abuse; and/or recognition as "vulnerable members of society" (i.e. sex workers, homeless or displaced people or those without any form of family or other support).

**P3** talked about the frustrations of trying to convince patients to attend life-saving treatment:

*You can have, you know, really depressing days where you've done everything. You've got that patient all the way through and then you get them to the door of the treatment and they say 'no'. (P3)*

**P1** commented about the importance of having an advocate, especially for high-risk patients who by definition, often lack familial or community support.

*They need an advocate with them... who is able to tell them again and again what was said... They might need somewhere to sit. They may need to talk to a stress counsellor at that point... Just so that they feel somebody knows what they're going through and can actually spell it out for them so they don't have to walk out the door and go "he just told me I have cancer; what the hell do I do now? (P1)*

The high-risk patient group numbers are high and the support role can be dangerous (including on-site visits to 'Black Power' Motorcycle Gang homes and known drug or prostitution areas). To cater for this, the Dunedin District Health Board has created a role for a specialist nurse to identify and support these patients. However, the role creation is part of a 'pilot' program with only three years of funding for its current stage. Without this program in place, and staff to run it, it is likely that many of these high-risk patients would die from otherwise treatable cancers.

### **3.2.6 Survivorship**

A breast cancer patient is considered a 'Survivor' from the moment of diagnosis until the end of life (Ullman, 2014). A growing number of people, who would be considered cancer survivors are currently living with a history of breast cancer (Mao et al., 2009). Due to population age and growth, the incidence of cancer is likely to continue to increase (Yabroff et al., 2004) and the scope of oncology specialists is possibly inadequate to address the broad spectrum of patient needs during cancer survivorship (National Academies Press, 2008). As more breast cancer patients survive past the five-year life expectancy mark, and longevity increases, other issues start to develop. Toxicity and detrimental side-effects from radiation and chemotherapy treatments may not appear until decades later (Ullman, 2014) as well as other chronic diseases that can occur after cancer therapy. Therefore, the issues surrounding survivorship will continually need investigation.

Post treatment surveillance is a crucial part of post-cancer care (Earle, 2006) because it assists with the detection of any recurrences and subsequent illnesses. However, this



does not always take behavioural, psychosocial changes, and late adverse effect detection into account (Hewitt et al., 2007).

Despite acknowledgment of the significance medical follow up plays in cancer survivorship care, the research in this area is limited (Mao et al., 2009). The Institute of Medicine report (National Academies Press, 2006) indicated that the health system appears fragmented and without a suitable strategy in place to assist cancer patients to navigate the many intricacies of survivorship, post treatment. With an estimated 30% of women diagnosed with breast cancer developing psychological morbidity within one year of diagnosis (NZGG, 2009), the weight of this problem exists for clinicians, researchers, and policy makers to redesign survivorship care.

*My experience in the cancer survivorship areas is not to take things for granted in terms of age and stage. I think that's one of the strongest things that I've learnt really. It's taught me just to be mindful and understand each one of the people differently. They're all different. (P8)*

Approximately 87% of patients in New Zealand are now surviving breast cancer (Ministry of Health, 2014). With advances in breast cancer diagnostics, early detection and treatment including drug therapy, the mortality rates have trended downwards between 2001 and 2011, falling by 19.6% (Ministry of Health NZ 2011). Therefore, it appears patients are being effectively supported and medically treated at the front of their breast cancer pathway. However, participants to this study conceded not enough is being done to prepare survivors for the end of treatment, to allow them to process their experience, adjust to their new 'norm' and reintegrate effectively back into their lives at the end of their cancer experience, whether that be in successful remission of their cancer or end of life care.

**P1** expressed this:

*You know, they've changed. Nothing will be normal again, not ever. And they don't know that! They don't relate well to their peers. They don't relate*

*at work and their lives begin to fall apart... I've seen women several years down the track and they go 'my life is falling to bits and I don't know why.' But it's simple. We don't have any survivorship programs. It's that basic and it's that simple. And we don't. And it's terrible. (P1)*

Perceptions of participants in this study suggest that many patients suffer a 'crash' approximately three to twelve months after treatment has finished. Despite some clinicians alerting patients to the prospect of this during the later stages of treatment, it seems patients are so focused on achieving remission, the weight of the warning is not often fully comprehended.

*I was working with a woman... I said, 'Do you want to see someone?' and she said, 'No.' And then, I think four months after her treatment she called me saying, "I'm really falling apart. This is really coming back to me. I thought I would be better but I'm not. I can't garden... I look terrible, you know I have no boob." And it was a realization she had now that everything's finished, I will go back to normal, it was just not happening. (P5)*

Participants **P1** and **P2** also described this crash:

*And you know at some point they're gonna crash. Absolutely. So, you just wait. And they do. (P1)*

*People around them said, 'Oh your hair's grown back, you should be fine now.' But they had really severe fatigue that they just couldn't get over. People don't understand that... Some men and women take a real hit after treatment... I think we don't look after people enough after they finish, and that's where I think The Cancer Society does really well. (P2)*

This crash has been observed in other studies and can affect survivors physically, psychologically and spiritually (Knobf, 2007). If left unaddressed, this can lead to a number of negative psychosocial outcomes, including: anxiety and depression (Ellis and

Tattersall, 1999); poor psychological adjustment (Bishara et al., 1997; Mager & Andrykowski, 2002); hopelessness (Sardell & Trierweiler, 1993); and reduced quality of life for survivors (Kreitler et al., 1995; Ong et al., 2000).

All of the participants interviewed in this study raised the issue of survivorship and its importance to the survivors, their caregivers and society as a whole. There are health professionals who are taking it upon themselves to create new initiatives to help assist survivors take a holistic approach to their return to life after cancer. Dr Lynette Jones is one of these health professionals. She has started a gym in Dunedin called “EXPINKT™” which is solely for breast cancer patients and survivors. Dr Jones suggests that patients who exercise during and after treatment are generally more successful in becoming fully functioning and contributing members of the community again. This program is a local personal mission, but it could be rolled out as a national initiative.

In 2012, The Cancer Society initiated a survivorship program called “Bridge to Health” which was designed to provide therapeutic support to survivors after treatment. Whilst this program is a positive step forward in a national approach to the survivorship issue, participants in this study acknowledged its limitations, i.e. that atypical patients are generally less likely to seek medical treatment, participate in effective knowledge exchange and engage in support opportunities within the community. Thus, the atypical patients referred to in this research are more likely to have poorer participatory outcomes in such an initiative.

The consensus of participants in my study is that more needs to be done to highlight the importance of this survivorship aspect of the cancer pathway, especially given research showing those who don’t reintegrate well back into society after cancer treatment can suffer from familial breakdowns, depression, an inability or reduced capacity to return to work and even suicide (Ong et al., 2000; Zachariae et al., 2003; Humphreys, 2000; Thorne et al., 2005).

*They put all these services in place and then they go, ‘See you later’. And it’s that moment when they come out of those acute services someone goes,*

*'God, I had this massive anxiety attack because there was no one there and I didn't know what to do.'* (P1)

### **3.3 Interpretation of Results**

#### **3.3.1 Approach and Measurements**

The data outcomes of this study outlined perspectives of health professionals about gaps and/or barriers to effective communication with breast cancer patients in New Zealand. The results of the qualitative research conducted via interviews with participants (n=11) defined categories related to gaps and barriers to effective communication and knowledge exchange. These were: Age, Gender, Culture, High-Risk and Survivorship. The unprompted highlighting of these categories supports the expectations of this study that related to atypical breast cancer patients as outlined in Chapter 1.

Participants in this study discussed their perspectives on the way communication occurs with breast cancer patients in New Zealand, and atypical patients in particular. Participants provided insight into their approaches and communication style with patients and how that proceeds along the cancer treatment pathway. Participants then responded about whether they modify their approach when faced with an atypical patient. Participants provided their thoughts around the barriers to effective communication and knowledge exchange between patients and medical and support service providers in New Zealand. And finally, participants provided recommendations on ways to improve communication, ameliorate barriers and/or be more inclusive in methods of communication, particularly to atypical patients. These results are further addressed in Section 3.3.4: Critical Evaluation and Discussion.

#### **3.3.2 Research Questions Answered**

The aim of this study was to collect, analyse and interpret perspectives on gaps in communication with breast cancer patients in New Zealand. This was achieved through

in-depth, face to face interviews with health professionals, in order to ascertain and explore their perspectives with communication with patients during the breast cancer treatment pathway. The results of those interviews were then evaluated and the emergent areas (or gaps) were categorised. The categories which relate to barriers to effective communication were identified as: Age, Gender, Culture, High-Risk and Survivorship.

The analysis of the data shows that there is a need for more inclusive methods of communication to be adapted. These include: multimedia and written literature resources that are gender, culture and age appropriate; review of mechanisms for linguistic barriers, so as to avoid compromising patient confidentiality; consideration of a more inclusive approach to online media with respect to gender; and a focus of importance on survivorship issues for measuring patient physical and psychosocial outcomes from the breast cancer pathway.

### **3.3.3 Research Approach**

The qualitative research design that was used in this study allowed the exploration of perspectives without the limitations of an existing framework (Creswell, 2013) in line with the research question: ‘What are perspectives of health care practitioners about gaps in communication with breast cancer patients in New Zealand?’ It is the intention of this study to provide a step forward for further research that will assist a wider spectrum of breast cancer patients.

Through in-depth face to face interviews, the data provided by the participants in this study revealed highlights, recommendations and concerns surrounding the way we currently communicate to breast cancer patients, especially to atypical breast cancer patients in New Zealand. The different approaches in communication depend on the type of patient presenting. There are numerous barriers to effective communication and knowledge exchange with breast cancer patients. And finally, they provided recommendations about what might contribute to improved communication methods, with a particular focus on those patients who may be considered ‘atypical’.

### 3.3.3.1 Rationale

An exploratory case study approach was utilised (Cassel & Symon, 2004). With individual perspectives being investigated in depth, the exploratory case study approach was deemed a robust framework for the narrative nature of my research, allowing for participants' perceptions to be examined in depth (Kvale & Brinkman, 2009). The interview process provided context and allowed further inquiry to areas of interest (Merriam, 2015).

### 3.3.3.2 Research Sample

Participants for this study included eleven health professionals and/or support service providers who are professionals who communicate with breast cancer patients in New Zealand. The population was drawn from the city of Dunedin, in the South Island of New Zealand. The employment spread of participants was diverse, including public, private and not-for profit employees.

The type of information sought for this research was whether health professionals adapted their communicative approach to the person in front of them, or whether they applied a 'one-size-fits-all' approach. If they did adapt their methodologies to be more culturally, gender, age or 'communication vulnerable' aware, how did they do this and what were their thoughts about ways to be more inclusive in our approaches in the future?

### 3.3.4 Critical Evaluation and Discussion

This study focused on communication with breast cancer patients in New Zealand, with a focus on the atypical experience. The approach to this research was to use an exploratory case study framework with content analysis applied to the findings. The overarching research question posed in Chapter One is: What are the perspectives of gaps in communication to breast cancer patients in New Zealand. This research highlighted the gaps identified by health professionals on the front-line of cancer communication dissemination and was able to categorise these into five key areas: Age,

Gender, Culture, High-Risk and Survivorship. With the development of inclusive, supportive and effective communication and knowledge exchange targeted to these gaps, communication with breast cancer patients, especially those considered atypical, should be improved moving forward.

In Chapter One the existing literature regarding breast cancer communication was reviewed and assessed. Whilst many studies have been done on one or all of the key areas identified, there is little research that has identified barriers faced in New Zealand and with a particular focus on the atypical patients identified in this study. The data from this study support and extend the existing knowledge in this field.

It is worth noting that the limitations of many of the studies conducted with a Cultural focus, were undertaken overseas. The Māori and Pacifica cultures are unique and more work should be undertaken to assess barriers and gaps within a more localised national setting.

Some of the useful findings in this research, were in the areas of Gender, Age and High-Risk.

GENDER: It was surprising to discover that New Zealand does not have any gender specific literature or tools/resources targeted towards males with breast cancer. This was introduced into the data from in-depth interviews with health professionals who communicate directly patients, as well as from the perspective of males interviewed for the creative component, one concerned about changes in his breast and one diagnosed with breast cancer in the creative component documentary “I’m Still Here” (Chapter Four and Appendix II):

*I’ve felt this all the way, that I was just a special case, that males didn’t get breast cancer. But at the same time I had it, there were four other males who had it, over a three month period. So, it’s not as rare as one thought.*  
Chris Bezett – “I’m Still Here” Documentary.

AGE: Another unexpected finding from this study was that New Zealand does not have any age specific literature or tools/resources targeted towards young adults with breast cancer. This was raised several times during the interviews with health professionals who coordinate the care of young adults in the breast cancer pathway:

*Trying to find the information that's age appropriate and targeted towards young people... It's not really out there... The information is written for [older] adults or written for children. It's not written for teenagers or young adults. (P10)*

This study has highlighted the additional issues faced by young adults with breast cancer. Targeted, age-appropriate communication resources should be produced.

HIGH RISK or 'COMMUNICATION VULNERABLE': This is a demographic that the researchers did not anticipate. Whilst it is noted that District Health Boards are applying methods to improve dips in attendance, knowledge exchange with health professionals and adherence to the cancer pathway for patients from a cultural perspective, the same should be applied for the high-risk patients who show poorer physical and psychosocial outcomes and show compromised outcomes for quality of life, due to the reduced effectiveness of the health professional-patient communication they experience (Siminoff, et al., 2006).

*She had lost her home, she was sleeping on the couches of men friends. We couldn't get her into appointments because we never knew which house she was at. (P3)*

A limitation to this study was the scope of participants and the shared location amongst them. It did not allow for diversity of communication approaches amongst different geographical locations within New Zealand. And whilst the perspectives of the participants to this study (n=11) was used to highlight new information, the data set is too restricted to gauge effects of barriers to communication on a national level.



### **3.4 Limitations and Future Research**

This research benefited from its use of health professionals who directly disseminate communication to breast cancer patients in New Zealand. The small sample size allowed for a thorough analysis of the data. It also allowed the researchers to recall elements of the interviews and to become intimately familiar with the in-depth responses provided by participants. It is our understanding that this research is the first conducted directly with health professionals and support service personnel to outline the five key categories relating to communication barriers, that clearly identifies the five categories of barriers or gaps to effective communication and knowledge exchange. However, the small sample size was also a limitation to this study.

Another limitation to this study was that a majority of the participants are localised in Dunedin, New Zealand. This means that the results are potentially biased to the geographical location of Otago in the South Island of New Zealand. Whilst the results presented here may be indicative of national issues facing patients and health professionals, further investigation on a larger scale is needed to confirm relevance of findings and recommendations.



## CHAPTER FOUR: CREATIVE COMPONENTS

### 4.1 Creative Components

The creative component of this thesis comprises of two sets of digital media (film) resources, one being a 26-minute documentary and the other being three 3-minute webisodes. These latter resources were designed and created to increase awareness of communication issues faced by atypical case-study patients during their breast cancer treatment pathway. The documentary is broader in scope, addressing survivorship in the full spectrum of breast cancer survivors.

The webisodes, provide perspectives of a young woman's breast cancer experience, a young male with a potential breast cancer diagnosis, and the recommendations of an oncologist urging fellow practitioners to utilise self-regulation and peer feedback of their communication skills in order to continue to improve.

The documentary called "I'm Still Here" explores perspectives of breast cancer patients who participate at the EXPINKT™ Gym, run by Dr Lynnette Jones, a Senior Lecturer in Physical Education at the University of Otago. The documentary provides a positive example of an exercise initiative that is directly addressing survivorship issues for breast cancer patients. It does this whilst simultaneously providing survivors with a safe and inclusive place to come together, share their stories and support each other in a close-knit community. It quickly becomes evident that this gym provides physical, emotional and psychological support for its participants, some of whom could be considered atypical breast cancer patients (a male, a young woman with small children and a Māori woman). In this documentary, we are able to explore first-hand, participants' experiences with breast cancer communication in New Zealand as well as gain insight into some of the barriers they face.

The aim of exploration of the experiences of the participants in the creative components of this thesis, was to provide patient perspectives on breast cancer communication.

These digital media tools were created with the intention that they will be watched by both the general public and health professionals online via the website for the Healthier Lives - National Science Challenge (<https://healthierlives.co.nz/>). The aim is to encourage discussion of effective knowledge exchange, particularly with health practitioners, and to provide a sense of connective empathy rather than a list of do's and don'ts. The aims therefore tie in with the research objectives outlined in Chapter 1. It is hoped that the resources inform and support improved communication about breast cancer.

Effective communication and knowledge exchange is key to allowing patients to maintain feelings of control over their cancer experience (McWilliam et al., 1999). Patient empowerment will only occur with continued support and tailored advice provided by health professionals (Bredart et al., 2015), continuing well after their medical treatment has concluded. Doctor-patient interaction is often complex and patients now recognise that they are not merely passive recipients of communication, rather they must seek information out and willingly participate in its communication (Lee et al., 2003). It is hoped resources produced for this thesis will enable patients seeking information to share in the experience of others and utilise the information to positively affect their behaviours in the future.

Once the cancer treatment pathway is finished, the connection between service provider and patient diminishes (Mack, 2009). Both patient and service provider are left to reflect on their experiences retrospectively. These creative components provide lasting testimonies that can be reviewed many times by anyone interested in this field. This assists in the support of breast cancer survivors feeling empowered to autonomously engage in self-monitoring and self-management of their health, as well as seeking out initiatives, like the EXPINKT™ program. And the resources can be used by health professionals to consider the recommendations made within the webisodes and the documentary, in relation to their own communicative methods as well as the communication offered in our current health care system.

## **4.2 Use of digital media to convey scientific information**

Studies show that utilising a combination of audio and visual mediums can assist with comprehension, understanding and increased memory (Berk, 2009). As society increases its trend of using digital media platforms to convey information, it is imperative that the information communicated is verified and reliable. Scientists are increasingly using narratives to convey substantiated data that not only evokes audience connection, but also improves empathic understanding and information retention (Dahlstrom, 2014).

## **4.3 Researcher / Filmmaker**

Health organizations are increasingly employing online media and technology to directly communicate to the public. This is in response to greater use and familiarity of online services by the community as a whole (Free et al., 2013; Thorn, 2014). Therefore, it was decided that an effective and complementary creative component for this thesis, would be webisodes created for online sharing. Based on the data provided in participants' interviews, the categories were clear. The aim of the webisodes is to provide personal insights on breast cancer communication from a case study (atypical) perspective, representative of some of those categories.

The creative component of this thesis is comprised of three 3-minute webisodes, filmed with the purpose of being uploaded onto the Healthier Lives National Science Challenge website as a tool to highlight the atypical experience with breast cancer communication, from the perspective of three individuals. The multimedia narrative resources follow the journeys of a young woman diagnosed with breast cancer at 32, a young man concerned about a breast cancer diagnosis and the specialist perspective from an oncologist and Cancer Society spokesperson from Dunedin Hospital. The intention of the narratives was to explore different perspectives of people who had come into direct contact with the cancer experience, in order to provide a sense of empathetic connection to an audience of health care professionals. These resources were designed

to address categories that emerged in the research process and are discussed in Chapter Three.

Research shows that doctors tend to lose their focus on holistic patient care over time, which can result in a decline in their communication skills (DiMatteo, 1998). The method of providing a filmed experience as a complementary tool to this thesis was to create a visual journey that could be explored and viewed as many times as the viewer wishes. The intention of the narrative of these webisodes was to encourage participant engagement and provide a sense of empathetic connection, rather than a list of facts, which can result in improved understanding by the audience (Dahlstrom, 2014). My aim was that these webisodes become a useful tool to encourage communication dialogue in the health care and support service sector and that dialogue is promoted as a result of their viewing.

“I’m Still Here”, the documentary, provides an exemplar of a health professional mitigating negative survivorship issues whilst promoting health, life and exercise in breast cancer patients, both during and post treatment. This documentary is the second of two creative components of this thesis. It is a complete film with a 26-minute duration including credits. The creative components or digital media resources included as part of this thesis can be used to educate and inform both health professionals and the public about the atypical breast cancer experience, and how to assist with issues related to breast cancer survivorship.

These digital media narrative components serve to provide the audience with empathy for the characters. I wanted to make sure it did not feel like the audience was being told how to feel, rather was seeing patients’ experiences unfold as they recount their stories. The documentary was designed as a visual aid to improve understanding (Dahlstrom, 2014) thereby, increasing the effectiveness of the health promotion message (Kreuter et al., 2010).

#### **4.4 Target Audience**

Professor Jim Mann, the Director of the Healthier Lives National Science Challenge was consulted about appropriateness of the webisodes as resource tools for health communication. Professor Mann indicated that these webisodes reflected the National Science Challenge's mission statement to "deliver the right prevention to the right population and the right treatment to the right patient." (<https://healthierlives.co.nz>) (J. Mann, personal communication, 7<sup>th</sup> November 2016). It is the expectation that these multimedia resources will be viewed by health professionals and support services personnel via the Healthier Lives website so that the content may stimulate discussion and reflection upon one's own communication style and methods for application with patients.

The documentary was, like the webisodes, designed for viewing online, with the aim of being uploaded to the Healthier Lives National Science Challenge website. This documentary was made to put faces to the people battling this disease and to highlight the incredible work being done by people such as Dr Lynnette Jones and the trainers at the EXPINKT™ gym.

#### **4.5 Research Design applied to Creative Components**

Additional ethical approval was not necessary for the filming of this documentary as all of the participants at the EXPINKT™ Gym are covered by the ethical approval for Dr Lynnette Jones for the Exercise Prescription Clinic (Category A #13/044) at the School of Physical Education, at the University of Otago. Interview participants signed consent forms prior to being filmed.

The use of narrative storytelling to convey health information is increasing (Frank et al., 2014) hence I desired to create digital media components that increased awareness about the issues of atypical patients and of survivorship that emerged in the research component. Both the webisodes and the documentary filmed for this thesis explore

experiences of breast cancer patients and health professionals in Dunedin, New Zealand. The documentary “I’m Still Here” highlights the importance of physical exercise in a supportive gym setting on mitigating negative survivorship issues for breast cancer patients. The storyline centres on Dr Lynnette Jones, a Senior Lecturer at the School of Physical Education at the University of Otago being inspired to create an exercise program after the death of a close friend with breast cancer. The aim of this resource was to highlight the importance of audience identification with its characters and provide narrative immersion that could affect behaviour. This design was used as narrative approaches transport audiences into the stories (Green et al., 2000). Studies show that identification with story characters can lead to positive changes to knowledge, beliefs and behaviours (Murphy et al., 2011).

#### **4.6 Link between Creative and Research Components**

These creative digital media components were developed to visually demonstrate the atypical experience with breast cancer communication. In conjunction with this, the webisodes and documentary were designed to provide real-world examples of effective ways in assisting with the promotion of health by highlighting exemplars of positive, inclusive communication methods, in an exercise prescriptive environment.

It was an exciting outcome when the male participant filmed for the documentary, Chris Bezett, volunteered (unprompted and unscripted) that his experience during his breast cancer pathway reflected what the research had shown. He noted that New Zealand men are not offered relevant literature relating to their breast cancer experience, that he felt shocked at his diagnosis as he didn’t know men could get breast cancer, and that he felt he must be a ‘special case’ but was surprised to learn there were three other men in Dunedin receiving treatment for breast cancer at the same time as he did. This highlights that whilst males getting diagnosed with breast cancer is still perceived as being ‘rare’, it does occur and their communication needs should be heard and addressed.



Dr Lynnette Jones, Director of the EXPINKT™ program commented how valuable it was to have a male in the program and that he didn't feel he was eligible to participate in the program because he was male. Yet the prerequisite for participation in EXPINKT™ is that you have breast cancer, which he did, and are referred.



*Figure 4.1 Dr Lynnette Jones (EXPINKTTM Founder) in "I'm Still Here" documentary*

*We also have seen a male breast cancer survivor. Interestingly, that was something he highlighted. Was that, everything's about 'women doing it for themselves', it's about women coming together... everything's pink. He actually asked the clinical nurse specialist to contact me, to enquire if he would be eligible to come into the program. And of course, he was eligible. And he fitted in here perfectly. Dr Lynnette Jones, "I'm Still Here" documentary.*

Chris provided fascinating insights into his diagnosis of breast cancer and the communication he received at the start of his cancer pathway:



Figure 4.2 Chris Bezett (Male breast cancer survivor), 'I'm Still Here' documentary

*I was given some literature that didn't really apply to males with breast cancer; it all related to females. Chris Bezett, 'I'm Still Here' documentary.*

Chris also described the difficulty in telling his wife and his daughter of his diagnosis:

*I told my daughter and my wife at the same time. Because we were going to see my granddaughter at school (gets visibly upset). We were at my daughter's house and I'd just come from the doctor. And I just told them I had breast cancer and we had to deal with it.*

In the documentary, Jones explained the importance of Chris's participation in the gym, not only to highlight the gender gap in the breast cancer pathway, but to assist in making him feel included in a female dominated world. His presence served as a reminder regarding the atypical breast cancer experience.

*He's certainly been a real eye-opener, for a lot of the women, but also for myself, in so far as you don't see so many people who fit outside of who we normally think is a typical breast cancer survivor. Dr Lynnette Jones "I'm Still Here" documentary.*

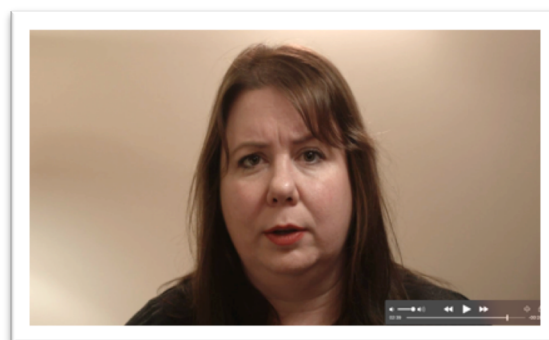
## 4.7 Webisodes: Case Studies

### 4.7.1 Case Study #1 – Emma Schranz (40 Years Old)

Diagnosed with an aggressive, hormone receptive tumour at the age of 32, I used my personal experience as a representative of the ‘young woman’ demographic. This webisode explains how a breast cancer diagnosis forced review of major life decisions in a very short period of time, decisions that had not yet been considered at great length prior to diagnosis. I also discuss the minutiae of contributing factors which led to an overall complicated and excluded feeling about the communication received during the cancer pathway of a ‘young woman’ atypical patient.



*Figure 4.3 Screenshots from Webisode #1 – Emma Schranz*



*Figure 4.4 Example of Direct Address in Webisode #1 - Emma Schranz*

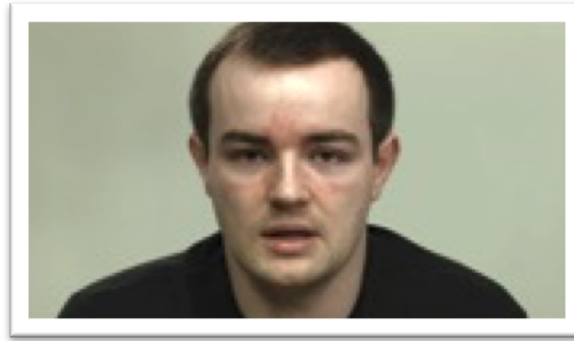
Writing, conceptualizing and filming these webisodes was an interesting and therapeutic process. Talking about my cancer experience on camera, in this, my seventh year in remission was liberating while at the same time re-connecting me to the content.

For Webisode #1, I travelled to Wanaka, Central Otago where I lived at the time of my initial breast cancer diagnosis in 2009. Logan Westwood provided camera and lighting assistance for the interview. The static interview took place inside a room by the lakeside, and exterior shots were at various scenic locations around Lake Wanaka and the township. The mountainous backdrops make for a dynamic and dramatic viewing experience when intercut with the static interview, providing supportive visual interest for the narrative.

#### **4.7.2 Case Study #2 – Regan Dodd (Male, 24 Years Old)**

In the second webisode Regan Dodd shares his thought-provoking experience as a young male in his 20's presenting with symptoms of possible breast cancer. He discusses the barriers he faced as he sought information online and then whilst seeking a medical diagnosis. Reflecting on his own experience, Regan then makes recommendations of ways to improve communication campaign methodologies to be more sensitive about and inclusive of gender.

Filming took place in several locations throughout the city of Dunedin, Otago in New Zealand's South Island. The cityscape provided a nice contrast to the wide-open landscapes in Webisode #1. It was my hope that the urban backdrop and Regan's youth would appeal to viewers who can identify with his story. I made sure to include pensive and quiet, thoughtful moments in this webisode to mirror these shots in #1, making the contemplative nature of the narrative consistent.



*Figure 4.5 Example of Direct Address - Screenshot from Webisode #2 – Regan Dodd*

In webisode #2, Regan shared his feelings of receiving what he perceived as indifferent communication, even though that indifference was technically and is typically correct. His account highlights the obstacles men may face in pursuing a breast cancer diagnosis whether they are societal, self-imposed or an actual dismissal by a health professional. And whilst the diagnosis outcome for Regan was a positive one, for approximately 20 men per year in New Zealand, the result is not so good. It is my hope that future diagnoses for men are as inclusive as possible.

#### **4.7.3 Case Study #3 – Dr Chris Jackson (Oncologist)**

Communication skills can wane over time; therefore, clinicians need to self-regulate their communicative training and seek regular feedback (Brown et al., 1999). Research shows that clinicians who lack communication training skills can have difficulty in recognizing and responding to patients' ongoing informational and emotional needs resulting in a negative patient perception (Levit et al., 2013).

In webisode #3, Dr Jackson emphasises the benefit of continued communication training and encourages health professionals to self-analyse their communication styles, get feedback from others and to seek additional education and training on communication styles and barriers so as to continue improvements.



*Figure 4.6 Example of Direct Address - Screenshot from Webisode #3 – Dr Chris Jackson*

Filming for this webisode took place in the Oncology department of the Dunedin Hospital in Otago, New Zealand. I also captured exterior shots of the building, the road and its surroundings to provide the sense of a busy city hospital. I decided to film Dr Jackson in his office, at his desk to maximize his familiarity and comfort in front of the camera. Dr Jackson was extremely supportive and was willing to share imagery from his line of work as an Oncologist, giving authenticity to the piece for the cut-aways.

#### **4.8 Documentary: “I’m Still Here”**

Documentary making is an engrossing medium, intruding into people’s worlds, probing their innermost feelings, their greatest fears, their triumphs, their losses and then resurrecting them all on screen for mass consumption. The process can have a lasting and profound effect on both the filmmakers and the subjects. With documentary, events have to be filmed as they are happening. If you miss them, they’re lost forever. That is what is so unique about this medium, that it’s connected unequivocally and existentially to its subject (Barbash & Taylor, 1997).

In view of this, and despite being an established screenwriter, I resisted the urge to heavily script the content of these digital media components. The unscripted approach was used in order to establish and maintain a spontaneous and personal connection with the subjects and ensure an authentic delivery of their accounts. It was considered imperative that the audience connect with the characters, especially since poor

character trustworthiness is potentially detrimental to content intentions and, response of the audience (Appel & Mara, 2013).

When considering the content of the documentary I wanted to ensure the participants' narrative would support the research contained within this thesis. However, this is impossible to achieve as documentary, by nature, is not 'scripted drama'. Rather, the information provided within a documentary is the account from the participants interviewed. Thus, I could not 'know' the direction of the stories.

#### **4.8.1 Storyline**

##### **INTRO**

In Dunedin, New Zealand there are a group of people forging their own path to wellness... proving that to really "live" is to live well... and not just "survive". We meet Dr Lynnette Jones who is a Senior Lecturer at the School of Physical Education at the University of Otago. After watching her close friend "Chrissy" undergo treatment for breast cancer and have some marked improvement when she exercised, Dr Jones was inspired to investigate the effects of physical education on breast cancer patients during and after the end of their treatment pathway. Since creating a paper for her hand-selected students to take, whereby research can be done on the gym participants, she has seen considerable favourable results. But her gym is a one-off. This is not a national initiative. Even with 8 years of solid research to back up the notion that all cancer patients (not just breast cancer patients) would have huge physical and psychological benefits from a supervised exercise training program, the EXPINKT™ program is a local creation, in Dunedin, New Zealand. One by one we meet the gym members, who share their poignant and heartfelt cancer stories. To tie in with the research question posed in this research, we include a Male, a Māori, and a young woman (with a young family) with breast cancer, to represent the 'atypical' demographic. Interviewees talk about the importance of this gym. What it means to them (so much more than just a place to work out) and how it would affect them if it were to lose funding and close down.

### CRISIS/ MID-POINT

Dr Lynnette Jones receives financial support for her trainer, Sommer to work one-on-one with the members of the gym. But as word spreads about the program, more and more referrals are made and more continue to come. With more than 140 participants at the gym - and that number increasing - the EXPINKT™ program is at breaking point. Without funding to support more trainers the gym relies on fundraising efforts from its members. But as the EXPINKT™ program grows in demand, more will need to be done to ensure its sustainability and growth.

### CONCLUSION

The Pot Luck. We finally see the scope of people Dr Jones' program actually effects. One by one they get up to make speeches about the power of the program "I feel it's daily saving my life". We see all of the cast mingling and laughing with people they now call friends. All bound together by a single disease.

Dr Lynnette Jones and the members of the EXPINKT™ gym are still here... as living proof that the fight against breast cancer is not just about diagnosis and survival.

It's about living... and living well.

#### **4.8.2 Recruitment of Actors/Participants**

Each of the three participants in the webisodes were given a copy of the Participant Information Sheet (provided to the interview participants) and provided with a general scope of the intentions and aims of this research prior to consent being sought to participate. With the first case study being myself, no consent was required. However, in depth discussions about any negative feelings or emotions that could come up as a result of the filming were had with the supervising researcher, Professor Nancy Longnecker prior to and upon completion of the filming process.



The second participant, Regan Dodd, expressed an early interest in being involved in the filming process. Known to the researcher/filmmaker, Regan was keen to provide a male perspective on the breast cancer experience. As a filmmaker himself, Regan was comfortable presenting that information on camera to an audience. Regan was at ease talking about an otherwise quite uncomfortable and very personal topic.

Dr Chris Jackson was approached to contribute a medical professional's perspective for the third and final webisode. As the spokesperson for the New Zealand's Cancer Society, Dr Jackson is well versed at speaking in front of a camera and was at ease while being thoughtful and concise in his articulation of the issues and how to address them. Provisions were made to ensure a minimal film crew would be present on set to minimise disruption to Dr Jackson's busy schedule and to maintain a diminished physical presence in the Oncology department at the Dunedin Hospital.

Poor character trustworthiness has been shown to be detrimental to story-consistent intentions and behaviour of the audience (Appel & Mara, 2013). Therefore, it was important to choose actors/characters that participants could connect with and, more importantly, trust. For the documentary, it was considered important that the subjects demonstrated a range of ethnicities, gender and age in order to provide further insights into 'atypical' experiences and that they displayed personality and integrity, so as to enhance audience engagement. The locations of filming had to be large enough to accommodate the film gear and crew and the locations helped to establish the 'world' (i.e. the gym in the case of the documentary).

I met with the participants at the gym, explained the requirements of filming and emphasised that their participation was voluntary. They were advised that if they were uncomfortable with any aspect of the questioning or filming they could advise me and I would either fix the issue or cancel the interview at any time. Each interviewee filled out a consent form and was provided with a copy of the list of interview questions to ensure they were comfortable discussing those issues.

## 4.9 Filming

Filming was done by experienced camera operator and filmmaker, Logan Westwood, on a Black Magic pocket Cinema Camera to give the webisodes a 'filmic' aesthetic. Sound was captured on a digital sound recorder with a directional microphone attached. Once filming had been completed, the micro SD cards were then uploaded to my computer and filed accordingly.

### 4.9.1 Cinematography / Technical Specifications

I had access to a Sony F55 Cinema camera and knew from the outset that was what I wanted the documentary filmed with. The F55 has a S35 size image sensor (equivalent to Super 35mm film) and records a wide dynamic range. This lends itself to a more cinematic image, which is evidenced throughout the film. We shot the film in Cine-EI Mode S-LOG3, which gives it an ISO of 1250; this means the image sensor is more sensitive to light than it would be at a lower ISO rating. This allowed us to capture the full 14-stops of dynamic range that this sensor is capable of. This allows for greater flexibility in Post Production, as the image is able to be manipulated via colour grading more robustly than an image captured at Television Broadcast standard (REC.709).

The F55 is also capable of shooting in slow-motion, which was what I wanted to use for the opening sequences and for shots of Dr Lynnette Jones in her office. Changing the speed at which the film flows not only shows technical skill but helps create diverse visual interest for the audience. For these slow-motion sequences, we filmed at a 100-150 fps (frames per second) which equates to 4-6x the normal speed. Our project frame rate was 25 fps. We used one lens, which was a broadcast zoom lens, the Canon CN7x17 KAS S Cine-Servo 17-120mm T2.95 (PL Mount). Utilising a zoom lens allowed us cover all our focal lengths using a single lens. This lends itself to documentary-making as we are not required to constantly change lenses during filming and allows for a more 'reactive' approach to the cinematography.

For the sequence where we track behind Dr Lynnette Jones as she walks down the corridor and into the EXPINKT™ Gym, we used a DJI Osmo. The DJI Osmo is a small camera mounted on an electronically controlled gimbal that stabilises any unwanted operator movement. This allows very smooth and fluid hand-held shots.

A full lighting kit was rigged for each individual sit-down interview, in a classic 3-point lighting style pattern. This constitutes a 'main source' (1), which is a big light source such as a window, or a direct light. The second light is a 'fill' light (2). This lifts the shadows which usually appear on one side of the interviewee's face. Lastly the Hair or 'Rim Light' (3) is designed to highlight and separate the subject from the background, which stops the image from appearing flat. This gives an improved sense of dimension.

The lighting kit consisted of 2x Redheads which are 800-watt, tungsten lights. We used quarter CTB (colour temperature blue) gels to match the lights to daylight. We also used a diffuser on the lights to soften the main direct light source as it is too harsh on a subject's face. Sometimes the main light source was a window, at other times it was a Redhead light, depending on our location. We chose to interview all of the gym members in the gym setting, utilising the natural light coming in through the windows to soften the image and highlight our participants' faces.

I decided on the idea of a 'direct-address' style for the interviews, whereby the interviewee would look and speak directly to the camera. This allows for a unique style of audience engagement, whereby we remove any barrier between the audience and the subject. This allows for a more conversational and personal type of approach, which challenges the audience to see the story through the eyes of the person telling it (Nichols, 2017).

We used lapel-mics connected directly to the camera to capture sound. This avoided echo in spacious locations. Each participant was given a lapel-mic which was lightly gaffed onto the skin on their chests, to best capture their dialogue.

From a directorial perspective, I chose to have our 'establishing' shot with each subject start as a wide shot. Then we would push in to a MCU (medium close up) for the secondary position, followed lastly by a CU (close up) for the harder more personal questions to create a sense of intimacy. Another integral part of filming for documentary is to capture the subject's hand movements. This allows for intercutting cut-away images over cuts in the dialogue in the editing process.

Most of the documentary was filmed statically, i.e. with the camera mounted on the tripod. However, for the final act, which took place at the 'Pot Luck' evening, I wanted to take a hand-held approach. Whilst this can appear a bit looser, this technique works well to help our audience feel like they are there, in the room with the participant. That also evokes a sense that this scene is less formal than the preceding interviews and that now we can all relax and let our hair down a bit. Again, this technique lends itself to documentary style filmmaking as it permits the camera operator to be reactive and observational in their shooting style.

#### **4.9.2 Access and Location**

The location for the documentary was the University of Otago's School of Physical Education and the EXPINKT™ Gym.



*Figure 4.7 Exterior School of Physical Education, University of Otago*

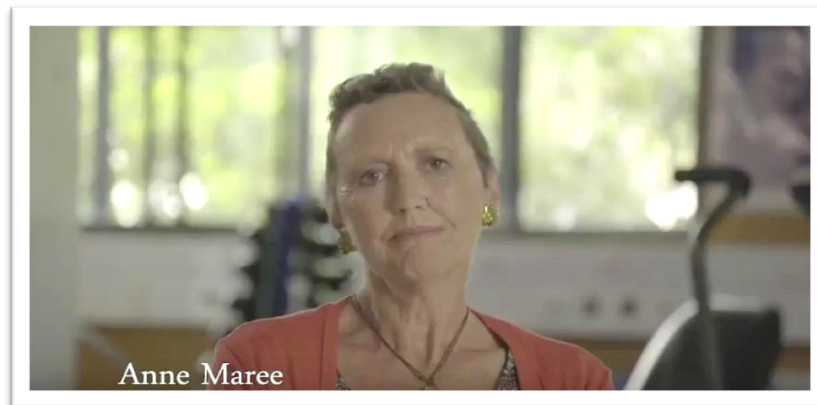
The EXPINKT™ Head Trainer, Sommor O'Shea allowed us access to the building for all of the varied scheduled interview times. Sommer assisted greatly in the scheduling process and acted as intermediary between myself and the participants of the gym. At all times, it was reinforced that participation in the documentary was voluntary, and that if participants had any issue with any of the lines of questioning that they could stop at any time. All of the camera, sound and lighting gear was transferred on and off location by myself with assistance of Logan Westwood.

Scenes involving Dr Lynnette Jones utilised a wider variety of locations. These included several around the University of Otago campus, such as her office at the School of Physical Education, Castle Street, the Clock Tower and the exterior of the Geology Department. Appropriate health and safety measures were adhered to at all times.

#### **4.9.3 Design – Direct Address**

My vision for the film's look, tone and feel, was soft, warm and hopeful. This was especially important in view of the potentially upsetting content. I decided upon a 'direct address' approach - where the interviewee looks and talks straight at the camera, rather than at an interviewer. This style was a little bold and unconventional, but for the webisodes and documentary to remain impactful, I wanted to ensure they felt more like a conversation than a lecture. Overall, the tone is meant to feel non-confrontational, rather it's more like a tête-à-tête discussion.

This approach has given the webisodes and documentary a sense of personalisation that complements the intimate and informative content.



*Figure 4.8 Example of Direct Address Style, "I'm Still Here" Documentary*

## **4.10 Editing**

### **4.10.1 Webisodes**

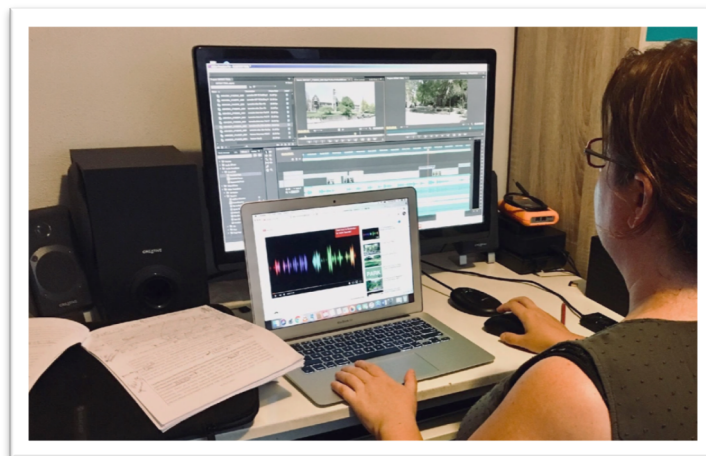
The compiled digital video and sound files were imported into Adobe Premier for editing. The visual and sound files were then synched on the timeline and then compiled into a three-minute narrative with a clear beginning, middle and end, for the webisodes. Secondary images captured at each location (cut-aways) were inserted as well as establishing and closing location shots, to provide the viewer with a clear three-act structure, despite the short duration of the videos.

### **4.10.2 Documentary**

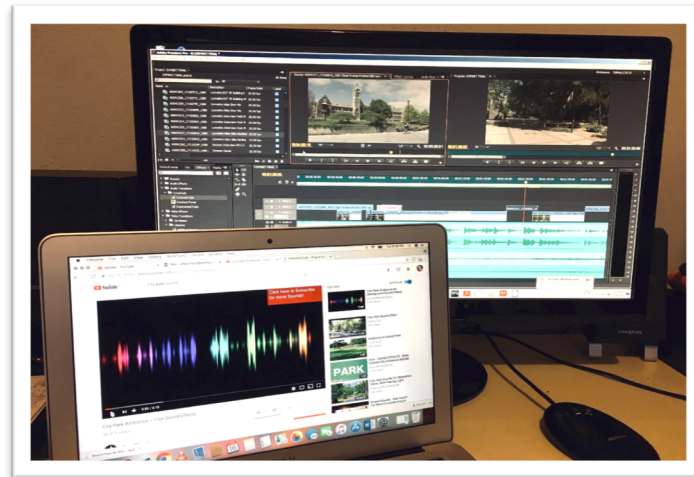
Due to the newer XAVC file format the Sony F55 produces and the age of the computer editing software I was using, I was required to use a software package from Snell Advanced Media called Alchemist, which would convert the camera files into something my computer would recognise, Pro-Res 422(HQ). Once that conversion was completed, the footage was loaded onto my editing computer in order to commence the editing process. I used Adobe Premiere Pro CS6 to edit the documentary.

Once the rough cut was done, the documentary was exported and shown to the supervising researcher, Professor Nancy Longnecker, Director of Filmmaking, Mr Ross Johnston and Teaching Fellow, Mr Steve Ting, from the Centre for Science Communication at the University of Otago for feedback and critique. With their notes, I made changes and re-worked the footage to a 'fine-cut' stage. Once I obtained hi-resolution logos for the Centre for Science Communication, the University of Otago, The National Science Challenge and The Cancer Society, I included title slots on the timeline along with appropriate credits and acknowledgements.

When I received approval from my Supervisors, I was able to export a final version of the film for a final sound check and for colour grading (Da Vinci). I applied some colour correction to the images that needed to blend in better and added some minimal contrast. I then burned the documentary and the webisodes to DVD's for viewing as the finished creative components to this thesis.



*Figure 4.9 Editing Process and Sound Design*



*Figure 4.10 Editing work station & Adobe Premiere Pro timelines*

## 4.11 Music

The scores for the Webisodes and the Documentary were created by Matthew Caradus, a Dunedin Music Composer, who has worked with me on several films to date. Matthew has an innate ability to put pictures into musical realm with sensitivity and understanding for the content he is writing for. When I first approached Matthew, and explained the topic for my thesis, he was more than happy to get involved.

Matthew and I set up several meeting times at his home studio, listening to reference music we felt fit the project tonally. From there we both agreed on a paired back, electronica score for the documentary. It was imperative that the music didn't feel like it was competing with the dialogue. Rather the music needed to support the way we wanted the audience to feel at any given time. Matthew and I came up with several descriptive words that would evoke the right emotions; hope, sadness, illumination, camaraderie and friendship. This formed the backbone of the score.

Once we had picture-lock, Matthew was given the film to work on. I inserted several pieces of reference music, which I had used during the editing process to assist me with the pacing of the edit. I found music that would rise and fall at the appropriate times and convey the messages I wanted to have support the dialogue we were hearing. I



provided this soundtrack to Matthew so he knew where I wanted the music to be highlighted or pared back. This has worked well for our collaborative process in the past.

Within a couple of weeks Matthew sent me the score for the film. He has a masterful way of writing simple haunting melodies and plays the instruments himself. The final score is a lovely piece that successfully draws in the audience, without leading their feelings in a manipulative way. Rather, the music enhances the intimacy and hope of the film.

#### **4.12 Limitations**

A limitation of this work is that effectiveness of the creative components has not been assessed. The effectiveness of these digital media tools could not be measured within the time constraints of this study, so narrative engagement has not been measured. Reliable measurements across a variety of health-related narratives and the conditions under which they are viewed should be conducted to inform most effective development of further resources in this area.



## **CHAPTER FIVE: CONCLUSIONS & RECOMMENDATIONS**

### **5.1 Conclusions**

This research aimed to investigate current communication practices and methods for knowledge exchange between health professionals and support service providers to atypical breast cancer patients in New Zealand. Through the exploration of clinical perspectives and observations, the desired outcome was to highlight specific areas that require further research, so as to improve inclusivity and facilitate effective knowledge exchange during the breast cancer pathway. This research conducted directly with health professionals and support service personnel clearly identifies five categories with specific needs for more effective communication and knowledge exchange.

The literature reviewed indicates that patients who receive reduced, misunderstood, exclusive, dismissive or ineffective communication at diagnosis, during treatment or at the end of the treatment pathway have poorer clinical, psychosocial and reintegration outcomes (Humphreys, 2000). Often atypical patients fall into this group. Research in this area demonstrates that the negative consequences of poor communication can be both substantial and broad in scope and that the patient groups/themes identified in this research represent demographics whose communication needs warrant further investigation and development of targeted resources. This was supported by the qualitative data gained from industry professionals who participated in this study.

All of the participants in this study discussed barriers to effective communication and knowledge exchange as being particularly related to Age, Gender, Culture, High-Risk and Survivorship issues. Each participant referred to these categories consistently throughout their interviews, even if that demographic didn't necessarily fall under their particular patient group focus. The themes that arose from the data were consistent and persistently raised as the prominent barriers to good communication and knowledge exchange between patients and clinicians in relation to the cancer pathway experience.

Cancer represents a crisis in the lives of those affected. The most pressing needs lies with facets of the crisis that can be prevented or ameliorated. The consequences of poor communication may include economic, social, psychological, emotional and collateral costs to the patient, the patient's support network, the clinicians, the cancer care system, and to the wider community as a whole.

Ignoring poor communication can potentially be costly (Thorne et al., 2005). Costs are not limited to the negative financial implications that cancer treatments' length and breadth has on patients. Costs can also involve the toll for society in coping with physical and psychological requirements of patients for months and even years after treatment has finished. Many participants acknowledged lack of finance and other resources as being the ultimate barrier to improving communication with atypical breast cancer patients in New Zealand. However, if focus is put upon improving existing methodologies to be more inclusive, holistic and positive for all patients, the financial, psychosocial and overall benefits to society will likely present themselves.

This research aimed to provide a foundation for continued dialogue with regard to communicative priorities and improving the quality of care during and after the cancer pathway. Most participants in this study reinforced the need to improve the way we communicate to anomalous patients. Therefore, it is hoped this preliminary analysis is successful in contributing to something larger. Inclusive, targeted and positive communication in cancer care is at the heart of that agenda.

## **5.2 Future Research**

More investigation is required to ascertain more specifically how barriers to effective communication and knowledge exchange with breast cancer patients affect them both physically and psychosocially. One goal of this study is to provide foundation information for future research that will result in patients exerting more control and mastery over their cancer experience (McWilliam et al., 1999). Ascertaining the communication needs and wants of atypical patients is a positive step towards

empowering both patients and clinicians to that end. The eventual aim of empowerment is action.

Interviewing patients over time, in line with their dynamic and changing communication requirements (including their post treatment needs) could provide invaluable data. This further research could then lay foundations for the framework for an improved communication model. To determine whether there are positive impacts and empowerment as a result of improved communication and social inclusivity of atypical patients, data collection will need to track progress and outcomes over time.

The creation of age appropriate resources and tools is a necessary step forward to improve communication with young adults with breast cancer. This avoids a one-size-fits all approach, as highlighted by many of the participants of this study. The needs of young adults are complex and dynamic and the information provided to them by health professionals and support services must reflect this. Having age-appropriate literature, online tools, DVD's and webisodes regarding the additional issues young adults face in their cancer battles would be a step towards bridging this gap.

Most participants in this research expressed the need to increase awareness of breast cancer issues facing men. This included breaking down of societal norms and pressures for men to be 'tough' and 'manly', which may be counter-intuitive to getting breast concerns or changes checked out as early as possible. Whilst studies have been done on males with breast cancer in New Zealand, it would be beneficial to this demographic to ascertain the communication needs and wants of males in the breast cancer world. This would ensure future resources and campaigns cater for an inclusive approach regardless of gender.

Several participants also highlighted a desire for continued improvements in the way we communicate to ethnic groups, including the need for more culturally appropriate professionals (especially registered nurses and translators). With greatly reduced Māori/Pacifika and Asian populations in the Otago region compared to their North

Island counterparts, participants felt the barriers to effective knowledge exchange with this particular group were considerable. It was noted however, that large strides have been made in the employment of specialists within the local district health boards and in the education and training of medical students. Further research on how communication approaches to these groups can be improved is important, especially considering their reduced registrations in national breast screening programs and their higher mortality rates.

High-risk patients come with a myriad of personal, financial, addiction and mental health issues that can prevent effective exchange of knowledge and support during the cancer treatment pathway. Their issues are complex and outcomes are poor. Several participants mentioned the importance of improved internal communication between clinicians and support services in order to address some of the issues high-risk patients face. This area encompasses a huge opportunity for additional research to be done.

Exploration of the financial, psychosocial, familial and social implications of Survivorship issues would be a considerably beneficial future research recommendation. The participants in this study confirmed that Survivorship is a key area of the cancer care pathway that warrants serious investigation. With The Cancer Society having implemented a Survivorship program “Bridge to Health” in 2012 it may be too soon to glean quantifiable results on its success. However, it is hoped that results from the benefits of this program become clear in the future and that they spawn other such initiatives.

### **5.3 Recommendations**

As well as continued research into the issues surrounding age, gender, culture, high-risk breast cancer patients and survivorship, participants in this study made professional recommendations on ways to improve communication with atypical patients. This study reinforced the need for patient advocates, especially for patients without adequate familial or social support. Health professionals need to address issues

surrounding ‘cognitive overload’ especially at the first and early specialist appointments. There is a need for a more inclusive communication and literature targeted to male breast cancer patients (i.e. including the disease in the ‘Movember’ male cancer awareness movement). There is a need for age-appropriate tools and resources specifically targeted to young adults with breast cancer. There is a need for a more diverse range of ethnically and culturally appropriate coordinators across all cancer streams. Health professionals need to be allowed more time, to listen more and not to rush. There is a need for improved inter-departmental communication within the district health board hospitals. Vast improvements in communication at the end of pathway to assist patients could assist all aspects of Survivorship. Survivorship programs that cater for all ages, genders, ethnicities and communication styles should be developed and adopted. There needs to be continued education and feedback for specialists, in order to ensure their skills can accommodate the different needs and communication styles of patients as they grow and develop over time. And finally, there is a need for improvement in communication between patients, families and medical staff regarding ‘End of Life’ and bereavement.

*From my feedback from many patients this survivorship care was really needed. I've such a strong sense that for a survivor to talk with any other survivor is so much more valuable than talking to a health professional... A peer support group would be probably better than the program run by the professionals. (P5)*

**P6** concluded with a sentiment of always seeking to improve methods for communication:

*You can't be the perfect doctor for every single patient. You do your best and you always try to be cognizant of what other needs they might have, but there are occasions when you miss something or you don't quite get it right for that particular person and their family. The important thing I always think is you've got to reflect on what could I have done better... and*

*hopefully it's a life of learning so you do get better and better at how you're approaching different situations. (P6)*

**P10** talked about the gaps that need to be filled moving forward:

*We really need to design something and put together something that addresses that issue, and this issue, and that issue... it's just such a huge gap, like information provision and education for young people with cancer and not just breast cancer, it's just a massive gap. There's just so much that needs to happen and at the moment, so little man-power to actually do it... We know it, we want to do it, we know it needs to be done... but we don't have enough time to do it all. (P10)*

**P3** finished with a call to arms for communication to be supportive internally as well as externally:

*I'm sure we burn out with the heaviness of the load that we do, but in saying that, we don't want to, because we love our jobs. So, we, as a team communicate... if we are not a strong supportive team, we will fail. (P3)*



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## **APPENDICES**



## **APPENDIX I: Webisodes #1,2,3 DVD**



## **APPENDIX II: Documentary “I’m Still Here” DVD**





## APPENDIX III: Coding Manual

Table 5 Instructions for Coding – used to code participant's interview responses into five overarching categories

Category	Description	Inclusions	Exclusions	Examples
<b>Age</b>	Young adults, under 45 years old	Young adults with any kind of cancer (not limited to breast cancer)	Breast cancer patients over 45 years old	<p>"With a younger woman, you are more likely to discuss fertility issues if they haven't had their families yet"</p> <p>"The impact is different to someone who's younger... it's more aggressive... so therefore the harder they hit it..."</p>
<b>Gender</b>	Males presenting with breast cancer	Males presenting with breast cancer-like symptoms and males with other forms of cancer	Gender fluidity	<p>"I'm quite surprised we get quite a high number of men referred with breast lumps..."</p> <p>"I think an awareness that male breast cancer exists is pretty prevalent, it's really out there..."</p>
<b>Culture</b>	Māori/Pacifika, Asian, indigenous populations	Ethnic minorities	Societal norms / pre-conceptions	<p>"It's different for Māori because you don't want to be showing your breast... with the woman who sits in the pew next to you when you go to church..."</p>
<b>High-Risk</b>	Vulnerable patients (i.e. with drugs/alcohol dependency, mental health issues, homeless/displaced people or without families)	Vulnerable Members of Society	Typical breast cancer patients with genetic pre-disposition to the disease (i.e. BRCA1/2)	<p>"Who are these people getting poorer outcomes and who are getting less support and getting less help. Yes, they are probably not asking, because culturally they won't, or geographically, or financially"</p> <p>"In terms of less typical patients, I do find it difficult... if you're having a complex conversation with someone who's really struggling intellectually..."</p>
<b>Survivorship</b>	Patient pathway (support) post treatment (i.e. in remission/cured or terminal stage)	Any gender, age, ethnicity and high-risk patients are included	Patients who didn't need support services or feel adverse effects from breast cancer treatment & communication	<p>"The patient feels like they've fallen off a cliff. They've have all this support, all this fuss made over them... and then all of a sudden they're out the door..."</p> <p>"our brief is to maintain contact for about two years post treatment (12-24-year olds with cancer) ... coz the wheels often fall off afterwards, when they've held it together, held it together and then they crash..."</p>



## APPENDIX IV: Participant Information Sheet

[D16/265]

[4/8/2016]



***“HEALTH PROFESSIONAL / SERVICE PROVIDER PERSPECTIVES ON  
CURRENT COMMUNICATION DISSEMINATED TO ATYPICAL PATIENTS  
DURING THEIR BREAST CANCER TREATMENT IN NEW ZEALAND”***

### INFORMATION SHEET FOR PARTICIPANTS

Thank you for your interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

#### **What is the Aim of the Project?**

The aim of this project is to explore communication experiences and methods for knowledge exchange between health professionals and service providers and atypical breast cancer patients in New Zealand. With reference to experiences and observations of health professionals and service providers, the researcher aims to review, assess and make recommendations to potentially improve provision of information to atypical patients during their diagnosis with breast cancer and treatment. The research aims to improve communication to be more inclusive of those who fall outside of what is considered the ‘norm’ of breast cancer patients (i.e. by including men, pre-menopausal women, Maori/Pacific, those who have not had families, who are single, young etc.). This research is being undertaken as part of the requirements for Emma Schranz’s Master of Science Communication.

#### **What Types of Participants are being sought?**

Health professionals and service providers who work with breast cancer patients are being sought for in-depth interviews.

#### **What will Participants be asked to do?**

If you agree to take part in this project, you will be asked to give a 30 to 60 minute semi-structured face-to-face interview with Emma Schranz at a time and place convenient for you. Emma will ask about your experiences of communication and knowledge exchange with atypical breast cancer patients in New Zealand. You will be asked if you have suggestions for improving communication with atypical breast cancer patients. The precise nature of the questions asked will depend on the way in which the interview develops.

The interview will be transcribed and a summary provided to you within a month of the interview to check that your views have been accurately represented. You may decide to withdraw from the project at any time without disadvantage.

### **What Data or Information will be collected and what use will be made of it?**

Ten to fifteen interviews will be audio taped and transcribed whilst maintaining anonymity. No identifying health information will be used. If any health information provided by you is useful in making a particular point, it will be summarised and provided to you for checking. Explicit written consent will be obtained before any health information is shared. The original data collected (voice recordings) will be securely stored on the University's secure server (Syncplicity), and only the researchers will have access. Identifying details will be stripped from the data files for use in data analysis. These anonymised data files will be stored on a password-protected server, which will only be accessible to the researchers.

Data files will be retained for five years or longer if required for publication in a peer-reviewed journal. The researchers will be contactable by phone or email for any further discussions, queries or relevant updates. Pending successful thesis examination, the MSciComm thesis will be available from the University of Otago library.

The Healthier Lives National Science Challenge and NZ Cancer Society are providing a postgraduate scholarship, which is enabling this research. There will be no commercial use of this data.

### **What if Participants have any Questions?**

If you are willing to participate, please contact Emma Schranz to make a time for a research interview. If you have any questions about our project, either now or in the future, please feel free to contact either:-

*Emma Schranz*

or

*Prof. Nancy Longnecker*

Centre for Science Communication

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This study (D16/265) has been approved by the University of Otago's Centre for Science Communication. However, if you have any concerns about the ethical conduct of the research you may contact the University of Otago Human Ethics Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

## APPENDIX V: Consent form for Participants



***“THE HEALTH PROFESSIONAL / SERVICE PROVIDER PERSPECTIVES ON  
CURRENT COMMUNICATION DISSEMINATED TO ATYPICAL PATIENTS  
DURING THEIR BREAST CANCER TREATMENT IN NEW ZEALAND”***

***CONSENT FORM FOR PARTICIPANTS***

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information [audio-tapes] will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. This project involves a semi-structured interview. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.
5. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

.....  
(Signature of participant)

.....  
(Date)

.....  
(Printed Name)



## APPENDIX V: APPENDIX VI: Questions for Participant Interviews

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### Questions for Participant Interviews

#### Protocol:

- Introduce self as researcher.
- Confirm participant understands terms to which they earlier consented, particularly:
  - purpose and length of interview,
  - nature of confidentiality,
  - that interview will be audio recorded and
  - that they can decline to answer any question and may withdraw at any time without negative consequence to themselves.
- Ask if they have any additional questions before we start.
- Ask questions in semi-structured format, where participant does not need to answer in suggested order. If a participant brings up topic earlier or raises new questions, maintain flow of conversation so that the participant is as relaxed as possible.
- At conclusion, thank participant and check if they have any further questions. Remind them that they'll get a summary of their interview within a month and have the opportunity to clarify or correct anything. Invite participant to get in touch if they have anything that they would like to add.

#### Questions (health practitioners and service providers):

1. How long have you worked with breast cancer patients?
2. What is your role?
3. How do you find communicating about breast cancer and treatment with patients? (*e.g.* explore, prompt: at the diagnosis, during treatment, at the end of treatment)
  - a. Do you think there are any barriers in communicating with breast cancer patients? (*e.g.* explore, prompt: geographical, etc.)
  - b. Is there any difference you employ when communicating with atypical patients?
  - c. Elaborate/ explore here. (*e.g.* Can you give any specific examples?)
4. How do you find communicating about breast cancer and treatment with carers/ family members?
  - a. Please elaborate. (*e.g.* Can you give any specific examples? )
5. How do patients and/ or carers respond when you are communicating about breast cancer and treatment?
  - a. Please elaborate. (*e.g.* Can you give any specific examples? )
6. Do you have any recommendations for health care providers or for patients that could improve communication during breast cancer diagnosis and treatment?
7. Do you have any other comments that you'd like to make?